



Abt Associates Inc.

**Cambridge, MA
Lexington, MA
Hadley, MA
Bethesda, MD
Washington, DC
Chicago, IL
Cairo, Egypt
Johannesburg, South Africa**

**Special Populations and
Their Use of Medicare
Information**

**Program Monitoring of
Customer Service and
Information Projects**

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***Prepared for*
Elizabeth Goldstein
Centers for Medicare and
Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244-1850**

***Prepared by*
Gary Gaumer, Ph.D.
Holly Korda, Ph.D.
Abt Associates Inc.
55 Wheeler Street
Cambridge, MA 02138**

Internal Review

Project Director

Technical Reviewer

Management Reviewer

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Executive Summary

This paper synthesizes monitoring and evaluation data about the National Medicare Education Program (NMEP) and the Regional Education about Choices in Health (REACH) program as they pertain to special populations. The primary issues are which sub-populations among Medicare beneficiaries need special attention in order to achieve the objective of “informed choice”, what targeting was actually done to these sub-populations, what kind of information they are getting, from whom, and which approaches may be most promising for meeting unmet needs.

Principle Findings

The principle findings are:

- CMS’s REACH efforts reflect an evolving mission and a maturing approach towards special populations. In our CY2000 REACH monitoring activities, we observed more active partnering and collaboration with community organizations to reach special populations.
- Though it is still early in the experience of the NMEP, and in spite of REACH efforts to give priority to special population needs, our site monitoring indicates that little attention is being directed by local information suppliers to special population information needs.
- Some identifiable sub-populations (or segments) of Medicare beneficiaries differ in the way they use Medicare information and the way they respond to the NMEP activities.
- There do appear to be unmet information needs among some sub-populations of beneficiaries.

Attending to the information needs of sub-populations is very much a local matter, where unmet needs can be identified, solutions fashioned and implemented, and where local partners can be engaged to help. Some evidence does exist of systematic (i.e. national) unmet needs for information for identifiable sub-populations, particularly for persons with urgent situational needs for information. But for chronically vulnerable sub-populations (like minorities, the poor, and those living alone) the evidence of unmet needs and restricted access to information sources is less systematic and may be subject to wide local variations — in such cases, national partnering and collateral development activities are of limited help. We find, however, that local information suppliers are, for the most part, not yet engaged to meet such special population needs, nor equipped to do so. It is encouraging to note that REACH monitoring has identified interest in several locations of concerted coalition building activities as an intensive way for making connections and providing information to sub-populations with special needs.

Special Population Segments

There is still a lack of consistency in thinking about special priority populations: who they are, what it means to be ‘special’, and what to do differently in trying to achieve consistently high

levels of informed choice across Medicare sub-populations. This lack of consistency in strategy is evident in the literature, in REACH planning and strategy materials, and in the work of information suppliers in the six sites we have been monitoring. To be sure, the strategy of REACH was to allow regions the flexibility to identify the special population needs and solutions, rather than imposing a programmatic view. But, the lack of an agreed upon framework for thinking about the types of special information needs for particular sub-populations contributes to inconsistencies in strategy about special needs at the local level.

Based on the general difficulty of getting to a consistent view of special populations, a new framework, one that includes four ‘special’ kinds of segments within beneficiary populations in every locality, may be warranted. We define these segments and their special information needs here, and summarize some of our results for each of these segments.

Communication Difficulty Segments — those persons who have difficulties communicating and using channels and messages designed for the majority of beneficiaries because they are culturally isolated and hard to reach, or because they have language barriers. This segment includes rural, non-English speakers, institutionalized beneficiaries, and others with cognitive impairments. Little is known from the literature or from the survey data about the special information needs of these kinds of sub-populations. While rural persons are lower users of covered services, there is nothing explicit in the literature to suggest that they suffer information deficits, nor is there evidence that they, or linguistic challenged sub-groups, are making poor choices or suffering in other ways from Medicare information deficits. While translated materials are becoming more available in local sites and at events, simply translating materials into other languages is likely to be inadequate in addressing the problems of linguistic minorities. Most community organizations and information suppliers in the sites we monitored do not have staff or resources to adequately address the needs of such groups, especially when language barriers exist. CMS’s support is important in meeting suppliers’ needs for providing information (materials, training, media).

Situational Segments — those beneficiaries who experience urgent, situational needs for information about Medicare. According to our survey findings and site monitoring reports, beneficiaries have a greater likelihood to search for information associated with occurrences of physician withdrawal from a managed care plan, a managed care plan’s withdrawal from Medicare, and change in health benefits.

One or more of these events occurred in CY 2000 for about 25 percent of the beneficiaries in our sites. These situations raise the annual likelihood of a beneficiary using information about Medicare about 9 to 14 percentage points, a relatively large effect. Other kinds of events that could create “situations” in the lives of beneficiaries were also generally found to increase information utilization. These “life events” occur for about 36 percent of beneficiaries in a year, and include: death of a spouse (no evidence of increase demand for information from this group), worsening of health status, and personal financial difficulty.

Socially Vulnerable Segments — those beneficiaries who belong to a population group that may be chronically vulnerable to the choices and complexities of Medicare itself — because they have limited means, inadequate education, or other issues. These groups include the very old and frail, the poorly educated, the poor, those in poor health, minorities, and persons who live alone, or are disabled.

We find that minorities and other socio-economically vulnerable groups are clearly less satisfied with their stock of information about Medicare, and are less knowledgeable about Medicare than other groups — and they experience choice difficulties and access problems for services. There are consistent suggestions from the literature that the very oldest beneficiaries, the poor, the poorly educated, those in poor health, and persons without supplemental insurance have problems coping with Medicare (access, satisfaction, choice difficulties).

Information usage by these groups is not uniform. Disabled beneficiaries tend to use information about Medicare more often, while the poorly educated, and the older beneficiaries, tending to use information less often than other beneficiaries. There is also evidence that the “other” minority group (including Asians, and some native Americans) tend to use information more often than other beneficiaries, and some indication that live alone beneficiaries less frequently use information sources (other than the handbook). Use by other vulnerable groups (African/Hispanic Americans, those in poor health) does not appear to be lower than other beneficiary groups.

Disabled beneficiaries are clearly special. They appear to be vulnerable to more urgent situational risks that might prompt needs for information, to be among the least satisfied with their information situation, and they certainly use information more frequently.

Special Opportunity Segments — some beneficiary groups may represent special opportunities for CMS to reach portions of the Medicare population in special ways or with high leverage (e.g., new enrollees, persons covered with insurance by large employers). New enrollees — those enrollees who are exactly 65 years of age — tend to know less about Medicare than other beneficiaries, are more satisfied with the information they have about Medicare and consistently search for information at rates much higher than other age groups. For the year 2000, for example, approximately 77 percent of new enrollees in our sites sought Medicare information, compared to 66 percent for all enrollees. New enrollees are more than twice as likely as other beneficiaries to use the Internet and counselors to find Medicare information, and appear more likely to use help-lines and the handbook as well. Some REACH partnering work with employer groups may be a promising approach to reach some of these persons, but the situation faced by many other “new” enrollees is not good. In depth interviews suggest that their information about Medicare and about sources of information is very limited, and their choice decision-making was not very analytical.

Medicare Information Suppliers and Special Populations

Three years into the NMEP campaign, the content and format of NMEP materials and activities continue to focus principally on the general Medicare population and disenrollees, with some translated materials. While this information appears to be widely available and distributed, information for special populations continues to be limited. Distribution is increasing at the six monitored sites, among interviewed partners, and materials and resources

are more evident in observed REACH activities and events. While impacts on beneficiaries are still difficult to detect, there does appear to be an increase in awareness and materials among information suppliers who are on the front lines in dealing with special population beneficiaries.

Special populations are not yet a primary focus of local information suppliers. Most organizations in the sites we monitored do not have a systematic approach or strategy for targeting special populations. Most local suppliers identified special population priorities based on Regional Office (RO) suggestions or local anecdote, and provided information to these sub-populations on a demand-response or incidental basis. While there is some evidence that *awareness* of the needs of special populations is increasing at the regional, state and local levels, noticeable efforts to address their information needs, to collaborate with community organizations serving special populations or to develop a sustainable Medicare information infrastructure for these sub-groups is limited. Addressing these needs is difficult, time consuming, and interpersonally challenging — and most organizations at the state and local levels are unaware of and ill equipped to address them.

Findings Pertaining to Partnering

Information providers who are attempting to serve special populations emphasized the importance of making connection with and working through community-based organizations that serve these populations, and encouraging these organizations to provide outreach and information through established and trusted networks in these communities. Partnering activities we studied as part of REACH 2000 also suggest that the ROs (and the REACH planning activities at the national level) are becoming more aware of the value of using local coalitions of non profit organizations to better reach some special populations, particularly the Hispanic and Asian Pacific Islander populations.

1.0 Introduction

This paper synthesizes Abt Associates’ monitoring and evaluation results about the National Medicare Education Program (NMEP) and the Regional Education about Choices in Health (REACH) program as they pertain to special populations. The Medicare + Choice (M+C) program expanded the set of plan options for Medicare beneficiaries, and increased the complexity of the choices that needed to be made.¹ The NMEP is a broad-reaching social marketing campaign intended to provide access to information to permit informed choices by beneficiaries. REACH is a component of NMEP, managed by the regional offices of CMS to deliver information to beneficiaries at the state and local levels. The overall objective of the NMEP/REACH programs is to enable informed choice by all beneficiaries. This requires 1) that beneficiaries should have ready access to information they need about Medicare, 2) beneficiaries should be able to understand the information they get, and 3) beneficiaries should perceive CMS as a credible source of information.

Since the Balanced Budget Act of 1997 (BBA) authorized NMEP, the Congressionally directed focus has been to promote market competition in Medicare by enabling beneficiaries to be informed consumers of health insurance options. The BBA specified a five-year implementation for NMEP (1998-2003) for beneficiaries to attain good understanding of the Medicare+Choice process. By design, 1998 and 1999 were the initial phase of the program which CMS targeted to make beneficiaries aware of new health plan options, prepare them for making an informed choice, and help them understand CMS’s role and mandate as it relates to Medicare. An emphasis of this early phase was that beneficiaries do not have to change if they are satisfied with the benefits they are currently receiving—that the choice is theirs.

The NMEP and REACH programs have, from the beginning, demanded that “special populations” be targeted in implementation work. Policymakers and program officials have stressed the importance of concentrating informational efforts on the more vulnerable members of the Medicare population, sub-groups of the beneficiary population for which special sensitivity may be required in order to meet their information needs. Barriers and inequities among beneficiary sub-populations regarding their ability to access and understand information needed for informed choice were recognized as potential barriers to the success of the M+C policy and program.

CMS has taken steps to develop materials and dedicate resources to dealing with special needs populations as part of the NMEP and REACH programs. For example, most materials that pertain to Medicare and M+C are translated into Spanish. The Horizons project is developing culturally appropriate information by working with African-, Asian-, Native- and Hispanic-

¹ The design of the traditional Medicare program recognized that health care was a local matter, and that personal circumstances and preferences about health care varied widely among the persons eligible for the program. The freedom of choice opportunities of the ‘major medical’ model of the coverage package provided a high level of parity across beneficiaries who may live in places with varying endowments of providers, and who have varying preferences and abilities to devote more of their own resources to health care. Concern about the equity of the program across sub-populations has grown with the increasing reliance on plans (and their gatekeepers) to provide equity of access to covered services, and the heightened dependence on beneficiary decision-making (requiring personal knowledge).

American groups. The Medicare web site and the toll free help-line offer Spanish services, and the web site has some material in Chinese as well. Special Employer and Caregiver Workgroups were formed in CMS's Alliance Network. The REACH program strategy has stressed the importance of doing events and activities that reach out to priority sub-populations of Medicare enrollees (see section 2.1 below for a summary). And other national partnering activities with the Administration on Aging, the National Association of Area Agencies on Aging, and the National Association of State Units on Aging are pursuing better methods for educating racial and ethnic minority seniors about Medicare.²

This paper reviews and synthesizes what is known about beneficiary populations that may have special information needs or are of special concern in maintaining equity across sub-populations served by the program. The primary issue here is what sub-populations among beneficiaries need special attention by the NMEP in order to achieve the objective of "informed choice" — and what do we know about the approaches that may be most promising for meeting these needs. The specific questions that guide us here are the following:

- § What are the special populations being used by CMS in planning and conducting NMEP and REACH activities — and what is the extent of variation across regions and localities?
- § Is there evidence in the literature that health or access to services suffers because of deficient information for these or other sub-populations?
- § What is the evidence about each sub-population's use of Medicare information, and how is this different in volume or substance from other beneficiaries?
- § How have the special populations been affected by the M+C program? How have the local networks of information suppliers been involving special populations in their work to assist Medicare beneficiaries in meeting their information needs?
- § What have been best practices in NMEP/REACH or by other non-Medicare agents in providing insurance-related information to special populations?

The report is exploratory in nature, intending to synthesize information from a number of separate monitoring activities conducted by Abt Associates over the last year. It is intended to provoke special studies or special monitoring actions in the future, aimed at the areas where there is evidence to suggest there may be unmet needs for sub-populations of persons on Medicare. The sources of data used in the report are:

- § Published and unpublished literature and reports including CMS intramural and extramural studies;
- § Monitoring activities and reports on the NMEP Monitoring and REACH assessment activities which include focus groups and in-depth interviews with RO staff, local officials, and partners;
- § Regional Office REACH business plans;
- § Survey Data from beneficiaries;
- § Enrollment and Eligibility (EDB) data from CMS, and

² These activities and other non-CMS initiatives of the Working Group for Culturally Appropriate Medicare Education are described in "Developing Culturally Appropriate Medicare Education Materials", B. Stevens, D. Yee, and J. Ortiz, Center for Medicare Education, Issue Brief Vol.2, No. 4, 2001.

§ Discussions conducted with new enrollees.

The survey and qualitative data reported here come primarily from a sample of six sites and the results may not be strictly generalizable to the program as a whole.

2.0 Defining Special Populations

With 40 million persons now on Medicare, there are certainly many identifiable sub-populations about whom we might worry about their knowledge of Medicare, and knowledge about the way to acquire such information when it is needed. Many sub-groups have certainly been the targets of special coverage rules, research and demonstration activity, and even special information supply programming. The list of candidate ways of “segmenting” the eligible population have included groups defined on the basis of:

- special health problems(disabled, frail elderly, ESRD, diabetics, etc.);
- where people live (rural, medically under-served area);
- socio-economic status (low income, dually eligible);
- age groups (including the pre-Medicare population);
- living arrangements (live alone, institutionalized);
- ethnic and racial minority groups;
- language barrier groups;
- persons faced with challenging life situations (end of life, death of a spouse, worsening health, etc.);
- situations about Medicare and insurance (involuntary disenrollees, newly eligible); and
- persons not eligible, but are caregivers for enrolled beneficiaries.

In addition to targeting these kinds of groups, there have also been programmatic activities aimed at information intermediaries (local partners, public interest groups, employers, providers, and the like) who are able to reach one or more of these groups with guidance or information.

For the NMEP, all Medicare beneficiaries have been identified as target audiences for Medicare information and outreach, consistent with the program’s objective to reach out to beneficiaries in every community and household nationwide. From the inception of the program there has been general recognition that certain groups would require special sensitivity in order for their information needs to be addressed. From the inception, it has also been clear that beneficiaries in all categories have unmet information needs about Medicare. So, the special unmet needs of the narrowly defined groups have been necessarily competing (for attention and for resources) with the general unmet needs for the larger group.

With only three years of NMEP program experience at this point, there is still lack of clarity about how special populations need to be considered as part of the informed choice mission of the NMEP: who are these special groups, what are their special needs, how should those needs be addressed differently from other persons? This lack of clarity or resolution is evident in the REACH planning activities and the literature we review below, and in the work of information suppliers in the six sites we monitor (reviewed in section 5.0 below). NMEP and REACH partners in most sites we have monitored do not have a clear picture of the priority special populations in their localities or what their information needs may be. Some sites report targeting populations identified by their CMS Regional Office; however, many sites reported that RO-defined special populations did not reflect local circumstances. Sites often identify

other sub-populations, ranging from military retirees, limited and non-English speaking immigrants, older and frail beneficiaries, and rural residents to more traditional demographic groups based on race or ethnicity.

2.1 Regional Office Targeting of Special Populations

Much of the programmatic attention to the special information needs of sub-populations falls to the regional offices and the REACH program. The data presented below on REACH strategic planning and the REACH 2000 activities suggests that there has been a trend over the first three years of REACH to place more emphasis on defining the sub-groups to be targeted, on meeting the special needs of those persons, and more evidence of using local partners to help meet these needs. But, the way special needs are identified and sub-populations targeted for attention still seems scattered and unsystematic. In this section we describe business planning and targeting of special populations by REACH 2000. We also provide more details of the REACH partnering activities pertaining to special populations.

REACH business plans (agreements between CMS Central Office and all of the ROs) reflect a maturing approach toward special populations in the REACH program. In the first year, 1998, some regions were selected to pilot test activities targeted to “hard to reach populations”. In 1999, each region agreed to identify a target population for each state, and to target activities toward these identified groups. In 2000, ROs were expected to use empirical evidence (demographic data, etc.) to select target populations and to identify activities to be delivered to ‘vulnerable’ populations. For 2001, planning has emphasized a commitment to target the face-to-face activities of the REACH program “toward vulnerable and under-served populations” and explicitly required that regions develop partnerships with at least two local organizations in order to “access a particular under-served community”. Looking forward beyond 2001, the REACH vision statement suggests that face to face events will remain priorities for reaching persons with “crisis” situations, and for “vulnerable and under-served populations”. This is clearly an evolving mission, with more emphasis on local discretion of priority sub-populations, more emphasis on empirical verification of need, and more emphasis on exploiting local partner support.

With the exception of the national efforts to provide translations (of materials and web site directions) and advocacy of “social marketing” approaches to implementing NMEP and REACH, there has been little official, national guidance about “special populations” — who these beneficiary sub-groups may be, what unique information needs they may have, which sub-groups of the population are priority targets, and how their information needs need to be best addressed.³ This lack of specification has been deliberate, leaving more discretion about targeting and methods. Consequently, ROs and local partners have been given wide latitude as to which sub-population groups are targeted and what approaches to reaching them are to be used. How these “special populations” are defined, the extent to which they have needs are that are problematic, and whether and how these needs are addressed remain controversial questions with important implications for CMS’s NMEP information activities.

³ While CMS has funded research to study some of these groups, there has been little national dissemination of guidelines to partners.

Table 2.1 below was prepared from CMS's outreach calendar database, a national registry of REACH events and activities.⁴ The purpose was to catalogue the kinds of special populations represented in the logged REACH events during the information campaign of 2000. Of the 471 activities (excluding activities for the disenrollees) on the log at the time we accessed the data, about 25 percent targeted a special population.

The data reflect the span of special populations that are the targets of beneficiary events. No evidence of priority is evident in these simple counts, though the most frequent targets noted were caregivers. Many sub-population groups were singled out in these event logs as "special".

Table 2.1
REACH Events Excluding Disenrollee Activities: July – December, 2000

	Number of events	% of total events
Number of events targeting general beneficiary population: *	363	77%
Number of events targeting special populations (categories below): **	118	25%
Total number of events targeting partners:*	21	4%
Total partner training events:	5	1%
Total number of events:	471	
Events targeting Special Populations:***		
African-American	34	7%
Asian-Pacific Islander	35	7%
Hispanic/Latino	34	7%
Native American	14	3%
Rural	29	6%
Low-income	24	5%
Disabled	12	3%
Employers	3	1%
Caregivers	38	8%
Pre-retiree	21	4%

* Note: may be both partner and beneficiary event.

** Note: partner or beneficiary events.

*** Note: more than one population may have been targeted for the events.

Source: CMS' online Outreach Calendar Database, 5/11/01

Regional Office plans for REACH are also a source of information on what kinds of sub-population targeting is being done. The named special populations, described in the business plans for REACH 2000, are diverse, ranging from state- and community-specific targets for particular beneficiary sub-groups to identification of special populations to be addressed throughout the region. These plans are profiled in the Table 2.2 below. For example, Region 1 (Boston) organizes REACH activities through state-specific beneficiary work groups, each of

⁴ The event log is known to be imperfect as an inventory of REACH events. However, our purpose here is to reflect the distribution of activities aimed at special populations. We have no reason to believe that general undercounts or overcounts (cancellations) of events are different for events that name special population objectives.

which provided input on special populations activities for their state outreach plan as reflected in Region 1's business plan.

In contrast, Region 6 (Dallas) and Region 9 (San Francisco) have identified specific beneficiary sub-groups in specific locales within states. Other Regions, including Region 2 (New York), Region 3 (Philadelphia), and Region 5 (Chicago) have identified broad racial/ethnic groups as special populations throughout their regions.

Most Regional Offices have identified special populations based on demographic status such as racial/ethnic community, rural residence, or low income. Three Regions (Denver, San Francisco, and Seattle) include disabled beneficiaries for special information efforts. Several Regional Offices describe special population segmentation using the proactive-passive-reactive social marketing model adopted by CMS for the NMEP campaign. Most Regions describe plans to apply this model and other social marketing techniques in their strategies and activities for REACH 2000. The Regions also described efforts to identify and target events for special populations using geo-mapping information provided through CMS's Central Office (CO).

The Regional Offices provide varying degrees of specificity about activities planned for general beneficiaries and special populations in their business plans. Some plans provide vague or general approaches such as "increase" or "continue" outreach to specific target groups. Others articulate specific strategies and tactics, and identify particular organizations they intend to develop relationships with to reach particular populations and communities.

All ten Regions described plans for developing or expanding partnerships and coalitions with community-based organizations that serve target groups. Most regions also described strategies involving print and broadcast media. Region 3 (Philadelphia) specified at least one media activity for each targeted special population sub-group, while Region 6 (Dallas) described plans for specific media outreach to channels known to serve special populations in specific states. Region 7 (Kansas City) also describes efforts to solicit media channels for Medicare information and outreach.

Most ROs are beginning to develop a more systematic approach for targeting special populations in the REACH campaigns. In our monitoring activities pertaining to the REACH program we observed more active partnering and collaboration with community organizations to reach special populations in 2000 than in 1999. We explore these activities in more detail in chapter 5.0, where partnering activities pertaining to special populations are described.

Table 2.2
CMS Regional Office-defined Special Populations:
Variations in REACH Business Plans for 2001

CMS Region	Special Populations Identified by regional officials	Core Strategies/Tactics
Region 1 (Boston)	<ul style="list-style-type: none"> - Rural and isolated beneficiaries in ME, NH, VT - Ethnic minorities (e.g., African Americans and Latinos) in CT, MA, RI 	<ul style="list-style-type: none"> - Use information-seeking model as a guideline to identify, prioritize and select special populations using community mapping; CT: passive beneficiaries through caregivers, distribution of materials to homebound, faith-based partnerships, new outreach venues, utility bill stuffers, media; ethnic minorities through partnerships with community leaders; MA: passives through supermarket promotions and provider and advocate training; ethnic minorities through multi-lingual, multi-media outreach; NH: rural and isolated beneficiaries through media, video for homebound; passives through direct mail; presentations for hearing impaired and French speaking; RI: passives through general outreach, billboards, newspapers; ME: passives through train-the-trainer for providers and advocates; forums for Native Americans, veterans, railroad retirees; VT: passives through country fair booths, distribution at pharmacies; rural and reactivities through hospital-based presentations.
Region 2 (New York)	<ul style="list-style-type: none"> - African Americans - Hispanic Americans 	<ul style="list-style-type: none"> - Continue partnerships with African American and Hispanic American communities; foster partnership development and growth of new coalitions to extend REACH efforts; independent media activities.
Region 3 (Philadelphia)	<ul style="list-style-type: none"> - African Americans - Asian Americans 	<ul style="list-style-type: none"> - Community mapping; building community-based coalitions; M+C activities focusing on special target audiences; one media activity per group; pilot outreach approaches for beneficiaries with barriers; assess language translation needs; distribute culturally competent materials; use of broadcast materials.
Region 4 (Atlanta)	<ul style="list-style-type: none"> - Active and passive information-seeking beneficiaries with limited education and income in rural areas with 700-1500 total beneficiaries - Active and passive information-seeking beneficiaries of Cuban heritage who live in the greater Miami area 	<ul style="list-style-type: none"> - Partner kickoff meeting; distribute monthly newsletter to 1300+ partners; build and email distribution list to 100 key partners; faith-based partnerships; create and distribute audio news releases; test direct mail (FL), outreach through Meals on Wheels, van tours.
Region 5 (Chicago)	<ul style="list-style-type: none"> - African Americans - Hispanic Americans - Asian American, rural, and homebound beneficiaries in areas without large numbers of African American or Hispanic American beneficiaries 	<ul style="list-style-type: none"> - Health fairs, events and activities, many targeted to special populations; use the results of social marketing to determine when, where, and how the targeted audiences want to receive Medicare information.
Region 6 (Dallas)	<ul style="list-style-type: none"> - Spanish-speaking/Hispanic Americans in NM and SW TX - Asian-speaking beneficiaries in Houston and Dallas - Native Americans in NW NM and East OK - Low income beneficiaries in Central OK, South AR, East TX, and NW and South Central LA - Rural beneficiaries in Panhandle of TX, Far West TX, Far NW OK, Far NE NM, and Central AR 	<ul style="list-style-type: none"> - Incorporate model strategic plan for developing on-going relationships with beneficiaries in each special target audience (radio, TV, training, collaboration, etc.); build community-based coalitions of groups serving target audiences; use direct mail, cable TV, community newspapers, internet; provide TA/consultation and materials to community partners and coalitions.

Table 2.2 (continued)**CMS Regional Office-defined Special Populations: Variations in REACH Business Plans for 2001**

CMS Region	Special Populations Identified by regional officials	Core Strategies/Tactics
Region 7 (Kansas City)	- Rural beneficiaries (defined as those counties outside MSAs within the 4-state region of KS, NB, IA, and MO)	- Use of Community Saturation Model to address rural outreach to specific communities re: multi-day program by RO staff and partners; leverage contacts with Congressional staff, state legislators, key partners to educate reactive audiences; find clearinghouses for audio messages, solicit media channels (TV, radio, print, solicit radio call-in); targeted training and outreach.
Region 8 (Denver)	- Hispanic Americans (CO and UT) - Disabled beneficiaries - African Americans (CO and WY) - Rural beneficiaries - Native Americans	- Expand partnership development, including community church organizations; facilitate partnering between local IHS representatives and already established state partnerships; identify and analyze partnership potential of special interest organizations and groups; identify new channels for special populations; work with Native American coordinator and organizations in SD.
Region 9 (San Francisco)	- Asian and Pacific Islanders (Chinese-SF Bay Area, Japanese-SF Bay Area, Korean-LA Area, Filipino-Southern CA, Las Vegas, Vietnamese/Laotian-Orange Co. CA, San Jose) - African Americans (AZ-Phoenix, CA-SF Bay Area, LA, Central Valley, NV-Las Vegas) - Hispanic Americans (AZ-Phoenix, Tucson, Yuma, CA-Bay Area, LA, Monterey/Salinas, San Diego, Sacramento, Central Valley, NV-Las Vegas, Reno) - Disabled Persons (throughout Region 9) - Rural beneficiaries (CA-Butte, Central Coast, Central Valley, Riverside, San Bernadino, AZ-Apache, Cochise, Coconino, Graham, Maricopa, Mohave, Navajo, Pinal, Yuma, NV-Churchill, Douglas, Elko, Humboldt, Lander, Lyon, Nye, Storey, White Pine) - Native Americans (Reservations in AZ, CA and NV)	- Translate materials for non-English speaking API communities; initiate contact with Native American organizations and tribal leaders; research production of video in English and Spanish for cable TV; conduct African American focus group re: Medicare education, outreach, materials; refine Train-the-Trainer course for partners serving underserved beneficiaries; allocate and prioritize resources using demographic data and information-seeking model; build community-based coalitions (employers, information intermediaries, faith-based); use of PSAs, media and publicity to special groups, partner with Congressional offices, work with veterans; utilize social marketing techniques based on information-seeking model.
Region 10 (Seattle)	- Alaska natives - Asian and Pacific Islander communities (API) (Western WA) - Disabled beneficiaries (ID) - Hispanic/Latino communities (ID, NW OR, Central and Eastern WA)	-Develop a model strategic plan for developing on-going relationships with targeted populations; establish faith-based network serving Hispanic/Latino communities in NW OR; establish coalition of organizations serving disabled in ID; develop and distribute video for AK Natives (funding permitting); continue relationship building with Filipino community using RO staff; provide media training to RO staff.

Source: Data obtained from Regional Office REACH 2000 Business Plans, date undetermined. Regional Office plans may be revised throughout the year by CMS Central and Regional Office staff. Core strategies/Tactics are summary points only and do not reflect all items provided in the plans.

2.2 Synopsis of the Literature Regarding Special Populations

There is a broad literature of published and unpublished studies regarding special populations and Medicare. This literature provides only quite general and limited answers to the questions pertaining to what special unmet needs for information characterize population sub-groups. Appendix 2 contains a summary of the most prominent studies reported in the literature about special populations and Medicare. We summarize those findings here before offering a general taxonomy for thinking about special populations for the NMEP (in Section 2.3).

There have been few careful attempts to define what is a special population for Medicare. The Institute of Medicine⁵ made an effort to do so, considering a wide span of evidence, but gave only controversial guidance as to who were the priority targets and why they were chosen. Policy experts, researchers and others have made several efforts to identify segments within the Medicare population with special information needs, summarized in Exhibit A.2 in Appendix 2. Attempts to define special population segments have focused on several types of criteria: 1) groups considered particularly vulnerable to consequences of poor choice (that may have consequences for cost, access, and quality of health services) due to their low levels of income or social isolation; 2) groups considered vulnerable due to cognitive or physical deficits to comprehension, or low literacy; 3) groups considered vulnerable due to cultural and linguistic disadvantage dealing with the healthcare system; and 4) groups considered vulnerable due to geographic or physical isolation (e.g., rural residents and homebound individuals) for whom choices and information channels are generally limited. Unfortunately, the literature provides a very incomplete and unsatisfying basis for believing that these criteria can be grounded in evidence of poor choice and unmet needs for information.

Some population groups have problems accessing services and using Medicare in the same way as other beneficiaries. Recently, the Kaiser Family Foundation and the Commonwealth Fund have focused renewed attention to the issues of inequity in U.S. health care. Evidence of service access problems for sub-populations is widespread. The Kaiser Family Foundation documented access problems for low-income beneficiaries, those without supplemental insurance, and those in poor health.⁶ MedPAC's study of the Medicare Current Beneficiary Survey (MCBS) showed that access limitations were present for these same groups as well as for minorities.⁷ Still, there is no evidence that links information deficits (or learning deficits) causally to the observed access problems of certain beneficiary groups or their poorer health status, or with their lower levels of satisfaction with the program.

In a recent survey of evidence about the health care and service use of the categories of Medicare enrollees, Gornick finds that low income persons and racial minorities have otherwise

⁵ Institute of Medicine, *Developing an Information Infrastructure for the Medicare+Choice Program: Summary of a Workshop*, Washington, DC: National Academy Press, 1999.

⁶ Henry J. Kaiser Family Foundation, "Medicare and Minority Americans," *The Faces of Medicare*, www.kff.org.

⁷ MedPAC, *Annual Report to Congress*, March 2000.

inexplicable poorer health status and lower utilization levels⁸. She says; “The unanticipated differences in the use of Medicare services across vulnerable subgroups of the elderly demonstrate that the implementation of a health insurance program does not, in and of itself, assure equal access to health care.” Medicare data indicate that black beneficiaries have fewer office visits and more ER and hospitalizations than whites. They also had fewer specialist visits than whites. Mammography rates are lower and black women are more likely to have later stage breast cancer. Gornick speculates that these differences may be related to information deficits. She suggests that there may be “cultures of advantage and poverty”, which causes some beneficiaries to expect high quality services, seek information about latest services, and are better able to work their way thru the health care system with networks of friends and professionals to obtain information about best providers and latest procedures. No testing of hypotheses is done about the extent of knowledge and level of programmatic expectations that might be consistent with the cultures of ‘poverty’ and ‘advantage’.

Some beneficiary groups are known to be less satisfied with Medicare. In one set of monitored sites Gold, *et al.*⁹ shows that beneficiary sub-populations in poor health and of low socioeconomic status (income, minority status, low education) are less satisfied with the type of Medicare coverage they have, and are more concerned about meeting cost obligations of that coverage. MedPAC drew quite similar results from the MCBS, emphasizing the lower levels of satisfaction with the program by beneficiaries in poor health and disabled.¹⁰

There is also support in the literature for the difficulties many beneficiary sub-groups have in making health plan/insurance choices under Medicare. A new study by Hibbard, *et al.*¹¹ identifies deficiencies in the choice behaviors of Medicare beneficiaries in general (relative to younger persons) and also finds that the frequency of choice error is higher for some sub-populations including the oldest, the least educated and the beneficiaries in poor health. Earlier work by Newman and Langwell¹² drew similar conclusions.

While there is no evidence linking access, choice errors, or satisfaction problems to information deficits, there is certainly evidence that some beneficiary groups have inadequate knowledge of Medicare and fail to understand the information sources pertaining to their choices. Earlier work by Abt Associates reported M+C knowledge deficits among the poorly educated, older, and poor beneficiaries.¹³ The work by Gold *et al.* (noted earlier) also documents limited general

⁸ “Vulnerable Populations and Medicare Services: Why Do Disparities Exist?” Marian E. Gornick. The Century Foundation Press, New York, NY. 2000

⁹ Gold, M., M. Sinclair, M. Cahill, N. Justh, and J. Mittler, *Medicare Beneficiaries and Health Plan Choice, 2000*. Robert Wood Johnson Foundation, January 2001, 120 pp.

¹⁰ MedPAC, op. cit.

¹¹ Hibbard, J, P. Slovic, E. Peters, M. L. Finucane, and M. Tusler, “Is the Informed-Choice Policy Approach Appropriate for Medicare Beneficiaries?” *Health Affairs*, Vol. 20, No. 3, May/June 2001: pp. 199-203.

¹² Neuman, P. and K. Langwell, “Medicare’s Choice Explosion? Implication for Beneficiaries,” *Health Affairs* vol. 18, no. 1, January/February 1999: pp. 150-159.

¹³ Carlson, Ken, “Knowledge and Satisfaction Among Beneficiaries in Six Sites”, unpublished, May 2000, Abt Associates (CMS Draft Contract Report 500-95-0065); Gaumer, G. and J. Wilwerding,

knowledge of Medicare and information sources (only 19 percent of beneficiaries knew that there were local information sources of unbiased counseling). This work identifies particular knowledge problems of sub-populations who have low income and low education, as well as caregivers with the same characteristics. Hibbard and Jewett¹⁴ reported on the most comprehensive and widely cited investigation of beneficiaries' knowledge and understanding of Medicare and managed care to date. Findings showed that 30 percent of their respondents knew almost nothing about managed care plans; only 11 percent had adequate knowledge to make an informed choice. Managed care enrollees had significantly lower knowledge levels of the differences between the two delivery systems. The study found that the most significant predictors of knowledge were income and education. Other studies also point to the related evidence of difficulties of certain beneficiary sub-populations being able to learn and comprehend information. Low education levels, cognitive limitations and poor health generally are mentioned (Newman and Langwell cited earlier).

There is very little published evidence in the literature about the demand for information by particular Medicare sub-populations. Gold *et al.* report use of informal sources (family, friends, doctor) are the main information channels, and that there is little awareness of formal channels. Community monitoring and focus group work by both Mathematica Policy Research (MPR) and Abt Associates point to the fact that demand for information appears to be higher when specific events require it. Persons who experienced important market situations (like involuntary disenrollment, or physician withdrawal from a plan, or an employer changing retiree health benefits) had higher utilization rates of Medicare information.¹

It seems clear that the very old, the cognitively impaired, persons in poor health, and those with little formal education have unmet needs for information. It is not so clear that unmet and differentiating needs exist for minority groups, or persons of low socioeconomic status. We offer some new information on these issues (Chapters 3.0 and 4.0 below).

2.3 Toward a Taxonomy of Special Medicare Sub-populations

Based on the literature, focus group reports, and on the activities we have seen in the field, we suggest that there may be four 'special' kinds of segments within the beneficiary population, each having different types of special needs for Medicare information. In general, beneficiary segments would warrant special treatment if they were known to seek information or learn in ways that were not as effective, compared to the mainstream beneficiaries. Or, they would be special if their needs for information are unique. To accommodate these special needs, population segments may warrant some unique channels of information, or some unique messaging, or both. The broad types of segments we believe warrant special treatment include:

"Utilization of Medicare Information Sources," May 2000, Abt Associates (CMS Draft Contract Report 500-95-0065).

¹⁴ J. Hibbard and J. Jewett, *An Assessment of Medicare Beneficiaries' Understanding of the Differences Between the Traditional Medicare Program and HMOs*. Public Policy Institute and American Association of Retired Persons, Washington, DC, 1998.

¹ Gaumer and Wilwerding, op cit.

- **Communication Difficulty Segments** — those persons have difficulties communicating using channels and messages designed for the majority of beneficiaries — because they are culturally isolated and hard to reach, or because they have language barriers.
- **Situational Segments** — those beneficiaries who have an urgent situational need for information about Medicare — because their plan dropped them, their doctor left their plan, they have a financial emergency, their health has worsened, their spouse died, or their employer changed the retiree benefits.
- **Vulnerable Segments** — those beneficiaries who belong to a population group which may be chronically vulnerable to the choices and complexities of Medicare itself — because they are very old, poorly educated, poor, isolated in rural areas, in poor health, live alone, or are disabled.

These three segments relate to special beneficiary needs. The last segment, below, is related to CMS needs and special information supply opportunities (though there may be ‘special’ needs of these beneficiaries as well):

- **Special Opportunity and New Enrollee Segments** — those beneficiary groups that may represent special opportunities for CMS to reach portions of the Medicare population in special ways or with high leverage (e.g., new enrollees, persons covered with insurance by large employers).

This last category of “Special Opportunity” beneficiaries is a residual group. To be sure, persons “new” to Medicare face a urgent situational need for information, and they could be grouped within the “situational” group along with persons who were involuntarily disenrolled from health plans and the like. We believe, however, that the “new” beneficiaries have markedly different needs for information (all must choose a plan for the first time), and are reachable using different information channels than the other situational beneficiaries. These channels are attendant to the initial enrollment process including the related SSA responsibilities. In this sense, the program may be able to ‘exploit’ the enrollment process (rather than some other process) to channel information to these persons. Likewise, Medicare may be able to channel information to other beneficiaries in this category such as the ‘about to retire workers’ and the persons with retiree health benefits by exploiting relationships with employer partners. Other pertinent sub populations may also be included in this segment such as those being targeted by REACH such as those persons utilizing public libraries or persons with parents on Medicare.

These four types of segments are, of course, not mutually exclusive sub-groups of the populations. They are used in the following chapters of this report, where we examine evidence of unmet needs for information about Medicare and restricted access to information sources. This framework for thinking about the special needs of sub-populations may also help in developing programmatic strategy about what types of priority targets need to be identified.

3.0 Indicators of Unmet Need for Information

This section of the report examines survey data about indicators of unmet needs for information for Medicare sub-populations. Here we examine indicators of unmet need including:

- results of a simple knowledge test,
- satisfaction with extent of information about Medicare, and
- the incidence of special situations that might require situational information.

These data come from a survey done by Abt Associates. The NMEP Community Monitoring Survey has been conducted as a random sample telephone survey in four cross sectional waves in six communities from Fall 1998 to Winter 2000/01. The most recent wave (January/February 2001) added four other communities and oversamples of minorities and involuntary disenrollees from managed care. Respondents answer questions about use of Medicare information sources, their knowledge of Medicare, their satisfaction with their knowledge of Medicare, and items relating to situational events during the past year that may be related to their need for information. The reader is referred to Appendix 1 for a description of the survey methods.

Table 3.1 below shows the FY2001 survey sample distributed among the various sub-populations we are able to study in this section of the report.¹⁵

The table reveals that the sub-populations are not mutually exclusive. That is, a particular beneficiary may be new, poorly educated and experience a death of a spouse — and appear in the set of persons identified for each of these three sub-populations. Obviously, there are significant correlations between some of the groups. We raise the issue here to make a methodological point that relates to the tables below. Using multivariate methods we sometimes adjust the measures for age, gender, year of the survey, and site in our pooled data set. But we do not try to measure the pure marginal effect of race or low income, for example, on the measures of interest. While this could be done, we would prefer that the measured difference in use of information (to pick an example measure) between the Hispanic group and all other beneficiaries be allowed to absorb all those important characteristics of that population group that might be different from the typical beneficiary.¹⁶

¹⁵ Note that the sample does not permit examination of sub-populations such as: rural populations, persons unable to complete the survey in English, persons over age 85, and persons in institutions.

¹⁶ The previously cited companion project reports by Wilwerding and Carlson do use such multivariate models to understand the marginal associations between these factors and measures of satisfaction, knowledge and information seeking.

Table 3.1
Special Population Size and Proportion of
2001 NMEP Community Monitoring Survey Sample

Population	Number of Interviews	Percent of 2001 Sample (weighted percent)
All Beneficiary Groups	5706	100.00%
Special Opportunity		
New Enrollees (aged only)	235	4.94%
Minorities		
African-American	521	3.43%
Hispanics	261	2.59%
Other Minorities	298	3.28%
Other Vulnerable		
Low income (<10k)	676	9.88%
Less Than H.S. Education	1016	15.53%
Poor Health (self reported)	408	7.02%
Live Alone	1687	28.63%
Dual Eligible	1260	18.36%
Disabled	430	6.81%
Situational Segments		
HMO Left Medicare	278	4.42%
Physician Left An HMO	310	7.34%
Employee Retirement Insur. Changed	458	11.64%
Spouse Died	216	3.78%
Personal Financial Difficulties	1123	16.82%
Health Declined	1399	24.98%

Source: Abt Associates' NMEP Community Monitoring Survey. This telephone survey of beneficiaries <86 years old was conducted in January/February 2001 in 10 communities, including Sarasota, Springfield MA, Dayton, Tucson, Olympia, Eugene, Minneapolis, Houston, Centre County PA, and Nassau County NY.

Notes: The sub populations are not mutually exclusive. The non white and disenrolled segments of the enrolled Medicare population were oversampled.

3.1 Medicare Knowledge

The unmet information needs of beneficiaries are difficult to assess directly. Through the survey we are able to test beneficiaries on a small battery of true/false questions about Medicare, as an indicator of their knowledge of Medicare. The issues pertaining to knowledge relate to the concepts:

- Medicare doesn't cover everything.
- You do not have to leave Medicare if you join an HMO.
- You can leave an HMO at any time.
- You can appeal an HMO's treatment coverage decision.
- Medicare covers colon cancer screening.

- Medicare covers mammography screening.
- HMOs can periodically change their fees and benefits.

We measured the frequency with which survey respondents scored above the median for each of these tests (value = 1), or not (value = 0). Using a regression, we tested the differences for each of the sub-populations in Table 3.1. The results of this work are shown in the first column of Table 3.2. These results note the instances where the knowledge scores are higher (+) or lower (-) than other beneficiaries, holding constant the age, gender, year and site of the respondent. Across all beneficiary groups, about 60 percent of beneficiaries test above the median on these items¹⁷ — and among the new enrollees, only about 54 percent test above the median (coefficient is 6 percentage points below the other beneficiaries). This gap in knowledge is an indicator of unmet needs for information.

The results here suggest that there are substantial knowledge gaps for some sub-populations. Persons in the Vulnerable population category are generally less knowledgeable than other beneficiaries, as measured by the fraction of the group's members who answer the questions correctly. Among the listed sub-populations, only the disabled (<65) are on par with other beneficiaries on the tested knowledge indicators. Very large knowledge gaps exist for the African Americans, the Hispanics, the Low Income Beneficiaries, and those beneficiaries not graduating from high school. In all cases, the knowledge gaps relative to other beneficiaries are in the range of 18-26 percent less than the average for all beneficiaries. Persons having significant, but smaller knowledge gaps (6-10 percent of the mean for all beneficiaries) are other minorities, those in poor health, those living alone, and the dually eligible. The new enrollees in the sample (age = 65), also have less knowledge on the tested messages, though the size of the gap for "new enrollees" is actually among the smallest of those for the sub-populations shown in the table.

The knowledge levels relative to all other beneficiaries are also shown on Table 3.2 for those sub-populations that experienced a 'situation' during the year that might have precipitated a demand for information. These situations include the beneficiary's managed care plan leaving Medicare, their doctor leaving the plan they are in, a prior employer changing retiree health benefits, a spouse dying, some personal financial difficulty or a situation of worsening health. For those beneficiaries experiencing an adverse 'insurance market event' (e.g., plan disenrollment, doctor leaving the plan, or employer changing benefits) there is clear association of the event with higher knowledge levels. The fraction of persons in these sub-populations having high knowledge scores is higher by 8-12 percent. Persons whose health declined are also somewhat more likely to be knowledgeable, though the difference with other beneficiaries is smaller than those experiencing 'market event' situations. We cannot say whether those persons having such events are more knowledgeable, or whether the event (and subsequent activities) led to higher knowledge levels. The latter is, of course, quite likely.

¹⁷ The threshold value of the median score was computed for all waves. The values for this sample are somewhat higher than for the larger sample for which the threshold was constructed, causing about 60 percent of the cases in this sample to exceed the threshold median.

Table 3.2
Adjusted Differences in Knowledge and Satisfaction

Population Group	Difference in Percent with Above Median Knowledge Score relative to all other beneficiaries	Difference in Percent Dissatisfied or Very Dissatisfied with the Information they have about Medicare relative to all other beneficiaries
Average of Dependent Variable for all Beneficiaries	60.5%	7.0%
Special Opportunity		
New Enrollees (aged only)	-6.0 *	
Minorities		
African-American	- 26.2 **	+4.2 **
Hispanics	- 18.6 **	
Other Minorities	- 9.9 **	5.7 **
Other Vulnerable Groups		
Low Income (< 10K)	-23.4 **	4.0 **
Less Than H.S. Education	-24.3 **	
Poor Health	-7.7 **	4.0 *
Live Alone	-4.5 **	2.2 **
Dual Eligible	-12.2 **	
Disabled		8.2 **
Situational Segments		
HMO Left Medicare	12.0 **	6.9 **
Physician Left An HMO	11.8 **	3.2 *
Employee Retirement Benefits Changed	8.4 **	
Spouse Died	-7.2 *	
Financial Difficulties	-7.3 **	10.0 **
Health Declined	2.8 *	2.7 **

Source: Abt Associates' NMEP Community Monitoring Survey of Beneficiaries. The data were pooled from the telephone survey of beneficiaries <86 years old as conducted in January/February 2000 and January/February 2001 in 10 communities, including Sarasota, Springfield MA, Dayton, Tucson, Olympia, Eugene, Minneapolis, Nassau County NY, Centre County PA, and Houston.

Note: Estimates obtained from weighted regression model, adjusting for age, gender, site and year. The table only reports differences that were statistically significant at $p < .05$ () or $p < .01$ (**).*

More problematic may be the sub-groups of persons who experience death of a spouse or personal financial difficulties. Both types of events may require reconsideration of insurance arrangements. Such persons experiencing these events in the past year are less likely to be knowledgeable (the difference with other beneficiaries is about 7 percent of the average). Because it seems unlikely that these events caused a reduction in knowledge, we believe this is evidence that persons experiencing these events are less knowledgeable (for whatever reason of selection).

3.2 Satisfaction with Information about Medicare

Table 3.2 also shows the differences in levels of beneficiaries' satisfaction with the amount of information they have about Medicare.¹⁸ The right hand column on the table reports

¹⁸ The question on the survey was "How satisfied or dissatisfied are you with the information you have about the Medicare program?" Persons answering dissatisfied or very dissatisfied were coded as '1'

statistically significant instances where persons in a sub-population have a lower or higher chance of being dissatisfied with their knowledge situation about Medicare. Positive results are to be interpreted as being "more dissatisfied".

Most segments of the enrolled population we study are distinctly less satisfied with their information situation than other beneficiaries. The disabled enrollees have a large 'satisfaction gap' of those groups studied on the table. Sub-groups of the beneficiary population experiencing special situations are also generally less satisfied than other beneficiaries. Persons involuntarily disenrolled from health plans, those with a physician who left a plan they were in, and persons experiencing financial difficulties or worsened health are all likely to be less satisfied with their information situation than other beneficiaries.

3.3 Events that Create Situational Need for Information

Do persons in different racial and socioeconomic groups tend to have disproportionately high needs for information, in part, because they find themselves more frequently exposed to the events and situations that might create situational needs for information? Figure 3.1 and Table 3.3 report the frequency with which the potentially vulnerable sub-populations experience the 'situation events'.

As shown in Figure 3.1, about half of all beneficiaries in the six site experienced one of the listed six situations during the past 12 months. The first three bars are summaries of the frequencies of certain types of events that we study here. The first bar shows that over 50 percent of beneficiaries experienced at least one of the six events in the last 12 months. The second bar shows that about 25 percent experienced an "insurance market event" like disenrollment, doctor leaving plan, or an employer changing retirement benefits. Of these events, the frequency of retirement insurance benefit changes is most frequently reported (about 13 percent of beneficiaries) and involuntary disenrollment from an HMO is the least frequent (about 6-7 percent of the beneficiaries in our sample). The third bar shows that about 32 percent of the beneficiaries experienced some 'life event' in the past 12 months, such as death of a spouse, worsening health, or personal financial difficulty. The last six bars show the frequency of each of the six events. Reiterating an earlier point, these events are not mutually exclusive.

and persons answering anything else were coded as '0' (including those answering don't know, or not answering at all).

Figure 3.1
Frequency of Situational Events

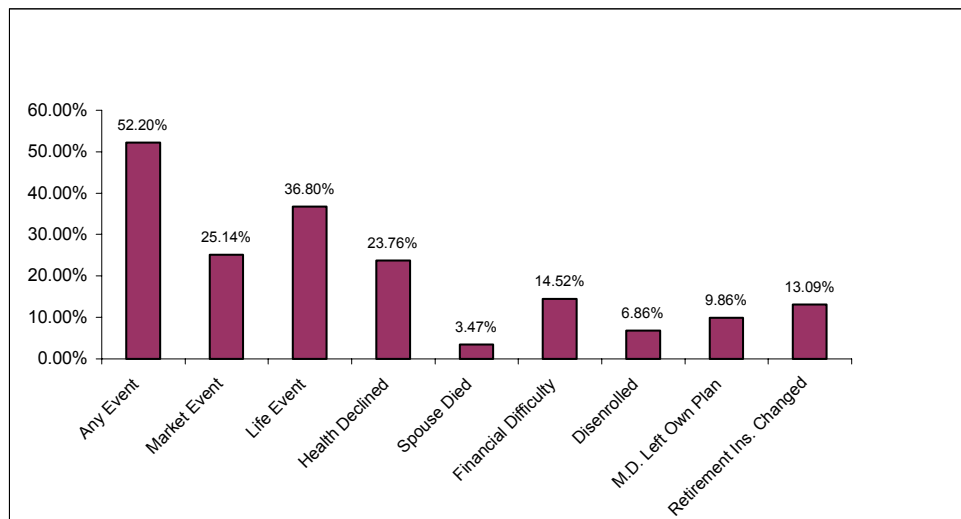


Table 3.3 shows the frequency of such situations for particular sub-populations. The bolded values represent instances where there is a statistically significant difference in the likelihood of particular situations (column) for the population sub group (row). Unbolded values represent cells where the frequency of occurrence of the situation is no different between the sub-group and other beneficiaries. For example, about 20 percent of new enrollees find themselves in the situation during the prior year wherein their retiree health benefits were changed by their previous employers. This is significantly higher than other beneficiaries, for whom about 8.8 percent experienced this situation.¹⁹ On the other hand, about 4.8 percent of Hispanics in our sample reported that their physician left a health plan they belonged to, though this is not statistically different than the beneficiaries who are not Hispanic.

Scanning each of the rows, we see instances where particular groups are more likely than other beneficiaries to find themselves in particular situations of concern.²⁰ Not surprisingly, most of the sub-groups are more frequently exposed to the situation of personal financial difficulty than other beneficiaries. Some other patterns stand out from the table, where sub-groups are exposed to higher situational risks. For example, the less well educated, those with low income, and those living alone are more frequently exposed to the situation of spousal death and personal financial difficulties (e.g., bolded, positive values).

¹⁹ The hypothesis test is done using a model pooling beneficiaries who are “new enrollees” with others, controlling for age, gender, and site. The value of 8.8 percent is only a very approximate value for the “non-new enrollees” in this case, since it represents the group of beneficiaries not included in any of the rows.

²⁰ Here, we are not really concerned about negative values, where the group is less likely to be subjected to a situational need for information.

Table 3.3**Frequency of Situations for Special Populations** (Unadjusted Averages)

Population	No Situation	HMO Left Medicare	MD Left Health Plan	Prior Employer Changed Insurance Plan	Spouse Died	Personal Financial Difficulties	Health Worsened
New Enrollees	.434	.043	.064	+.196	.008	.200	.179
Disabled	.284	.047	+.065	+.107	-.014	+.467	+.409
African-American	.414	.042	-.040	-.056	.038	+.344	-.209
Hispanics	.392	.064	.048	.076	.044	+.280	+.324
Other Minorities	.433	.034	.054	.097	.054	.235	.279
Low Income (< 10K)	.331	.047	.040	-.062	+.056	+.432	.268
Less Than H.S. Education	.424	.058	.044	-.063	+.051	+.280	.241
Poor Health	.164	.037	.051	.118	.032	+.434	+.630
Live Alone	.409	.047	.045	.068	+.100	+.245	-.220
Dual Eligible	.475	.050	.053	-.062	.032	+.213	-.219
Other Beneficiaries	.048	.051	.063	.088	.011	.014	.258

+ = percentage is larger (p<.05) than the average for all other beneficiaries using a multivariate model to adjust for age, gender, year and site.

- = percentage is smaller (p<.05) than the average for all other beneficiaries using a multivariate model to adjust for age, gender, year and site

Source: Abt Associates' NMEP Community Monitoring Survey of Beneficiaries. This telephone survey of beneficiaries <86 years old was conducted in January/February 2001 in 10 communities, including Sarasota, Springfield MA, Dayton, Tucson, Olympia, Eugene, Minneapolis, Houston, Centre County PA, and Nassau County NY.

The good news from Table 3.3 is that none of the vulnerable groups we examine is different than other beneficiaries in their risk of being involuntarily disenrolled from a health plan. We caution that these results are based on self-reported disenrollment (not based on EDB data) and the survey sample is drawn from only 10 sites across the country, and certainly is not representative of the program overall.

The revealing news from Table 3.3 is the situational risks faced by disabled beneficiaries. The table shows that this group has higher risks of exposure during the prior year to four situational events; their doctor leaving a plan, their previous employer changing retirement health benefits, personal financial difficulties, and worsening health. This pattern suggests that the needs of the disabled beneficiaries for information about Medicare during the year is likely higher than other beneficiaries. Other groups (except the other minorities) have elevated risks of one or two types of situations.

In our six monitoring sites, EDB data show something different from the survey about involuntary disenrollment, indicating that the burdens of disenrollment fall inadvertently, but certainly disproportionately on the Hispanic population. Table 3.4 below shows that Hispanics are much more likely than other named groups to have enrolled in managed care (38.5 percent compared to an average for all beneficiaries of 24.5 percent), causing the involuntary disenrollments of 2000 to disproportionately burden this beneficiary segment (over 7 percent of the Hispanic beneficiaries experienced involuntary disenrollment, against an average for all beneficiaries of under 5 percent).

Table 3.4

EDB Data on the Distribution of Managed Care and Disenrollment Across Sub-populations, Six Study Sites

(parentheses is disenrollment as a percentage of managed care enrollment)

Population Sub-group	Percent Enrolled In Managed Care	Percent Involuntarily Disenrolled	Proportion of Enrollees in the Six Monitoring Sites
White	24.8	5.0 (20.2)	91.9%
Black	15.3	2.6 (17.0)	5.2
Other	22.6	4.6 (20.4)	1.0
Asian	25.8	5.8 (22.5)	0.4
Hispanic	38.5	7.1 (18.4)	1.6
Disabled	14.9	2.8 (18.8)	12.7
New Enrollees	21.7	2.4 (11.1)	4.6
66-74	28.5	6.3 (22.1)	39.6
75-84	24.9	4.7 (18.9)	32.6
Over 84	21.0	3.7 (17.6)	10.6
Males	23.7	5.0 (21.1)	43.6
Females	25.1	4.8 (19.1)	56.4
All Beneficiaries	24.5	4.9 (20.0)	100.0%

Source: CMS Enrollment Data Base, February 2001.

3.4 Satisfaction and Knowledge Summary

To aid in the interpretation of the indicators of unmet needs for information reported above we have prepared Table 3.5 below. For each of the vulnerable groups and the situation groups the table describes the pattern of the two indicators of unmet needs: knowledge gaps and satisfaction differences, as we reported in Table 3.2 earlier. For example, persons who experienced the situation of their employer changing their retiree health benefits are, relative to others, not dissatisfied with their information about Medicare and they are also not less knowledgeable about Medicare.

From these data we would conclude that the groups in cell (1) are not a problem, and have on average, no unmet needs relative to other beneficiaries. These persons are more knowledgeable and are satisfied with their situation with respect to Medicare information. The needs of the group of population segments in cell (4) are also clearly known; knowledge levels are not as high as other beneficiaries and their satisfaction levels with program information are lower than other beneficiaries. These persons have unmet knowledge needs, and they recognize it. These persons are clearly priority candidates for special targeting of information programs. In the context of the taxonomy, the groups in this cell are considered socially 'vulnerable' in many ways, well beyond the scope of the Medicare program or NMEP.

Table 3.5
Summary of Findings about Knowledge and Satisfaction Situation of
Particular Sub-populations

	Knowledge level equal to or exceeds other beneficiaries	Knowledge level not as high as other beneficiaries
Satisfaction level with Medicare Information is equal to or exceeds other beneficiaries	Employer changed retirement coverage(+) 1	New Enrollees(+) Hispanics Did not finish high school(-) Spouse died Dually eligible 2
Satisfaction level with Medicare information is not as high as for other beneficiaries	Disabled(+) Involuntary Disenrollees(+) MD left plan(+) Health Declined(+) 3	African American Other Minorities Low Income Poor Health Live Alone Financial Difficulties(+) 4

+ Higher Usage Rate for Medicare Information (see Table 4.5 for details)

- Lower Usage Rate for Medicare Information (also from Table 4.5)

Source: Table 3.2 above, which is based on NMEP Community Monitoring Survey of Beneficiaries. This telephone survey of beneficiaries <86 years was conducted in January/February 2001 in 10 communities, including Sarasota, Springfield MA, Dayton, Tucson, Olympia, Eugene, Minneapolis, Houston, Centre County PA, and Nassau County NY.

The final two cells are also interesting. The groups in cell (3) have better knowledge levels than other beneficiaries, but are still not satisfied with the level of information they have about Medicare. It is possible that these persons have been disappointed with aspects of the program or are angry about their information situation, as revealed by circumstances. These persons are largely situational users of information, with higher usage rates.

The groups represented in cell (2) might be seen as having an “information need awareness problem”. Their knowledge indicator scores were lower than for other beneficiaries, but they are as satisfied as other beneficiaries with their information situation. This situation would contribute to a passive complacency about demanding information. Clearly there are communications problems with the sub-populations in this cell.

3.5 Digression on Involuntary Disenrollees

Because of the importance of managed care plan terminations in 2000, we examined the disenrollment experience in some depth through the NMEP Community Monitoring Survey done in Jan/Feb 2001.²¹ Through a special sample of disenrollees selected from the EDB, we asked respondents about a number of awareness and satisfaction issues, some of which are shown on Table 3.6 below. The reported signs and significance levels indicate whether the particular sub-population is different than other beneficiaries who were also involuntarily disenrolled. This analysis was not able to include some of the sub-population groups we used earlier due to inadequate sample size. Here, only the statistically significant results are shown for the five sub-populations for which sufficient numbers of observations are available.

A number of indicators point to gaps in knowledge and process pertaining to sub-populations. The key awareness outcomes (awareness of disenrollment, awareness of plan’s letter) are a systematic problem for some of the sub-populations (African-Americans, Other Minorities in particular). For the race/ethnic minorities, the letter from the plan is an ineffective tactic; either persons don’t recall receiving it, or they find it difficult to understand.

Results relating to satisfaction are important as well. The racial/ethnic minority groups have satisfaction problems, both with the amount of information they had to deal with the disenrollment situation, and with the resulting new plan.

The survey results pertaining to disenrollee decision-making also point to differences that may be important in social marketing. When asked *what factors were important for considering Medicare insurance options last year*, the coded responses were as follows (percentages responding to particular items are in parenthesis — and they do not add to 100 percent due to the fact that multiple items could be mentioned):

²¹ A separate companion report was prepared by Oren Grad and Andrea Hassol on “The Disenrollment Experience of Beneficiaries in Six Cities”, Abt Associates, July 2001. The results in this section are extracted from that report, which is based on survey data on disenrolled beneficiaries.

White Enrollees
Lowest cost (35.6)
Best Rx (28.7)
Keep doc (18.9)
Don't know (14.7)
Other (11.2)

African-Americans
Best Rx (37.5)
Keep doc (30.2)
Don't know (20.8)
Other (19.8)
Lowest cost (13.4)

Hispanics
Don't know (38.8)
Best Rx (27.1)
Lowest cost (15.6)
Keep doc (14.2)
Other (7.3)

Table 3.6
Special Populations and Disenrollment Outcomes
(adjusted differences between indicated beneficiary group and other disenrolled beneficiaries)

Measure	African Americans	Hispanics	Other Minority	Less Than HS Diploma	Low Income (<10K)
Awareness of Disenrollment	- *		- *		
Awareness of Receiving Disenrollment Letter from Plan [^]	- *	- *	- *	- *	
Found Disenrollment Letter Helpful [^]				+ *	
Found Disenrollment Letter Easy to Understand [^]	- *	- *	- *	+ *	
Used Info Sources Named in Disenrollment Letter				+ *	
Used <i>Medicare & You</i> Handbook					
Noticed Cost- Quality Comparisons in Handbook			- *		- *
Overall Satisfaction with Information	- *		- *	+ **	+ **
Satisfaction with Replacement Insurance [^]	- **	- *	- **		+ **

* p < .05 ** p < .01 Regression models standardize for age, sex, site and occasionally other factors including knowledge score and health status.

[^] models where health status was included in the model and positively correlated with the measure as stated (persons in poor health are less aware, less satisfied, etc.)

Source: "Involuntary Disenrollment from Medicare Managed Care Plans" Experiences of Beneficiaries in Six Communities", Oren Grad and Andrea Hassol, Abt Associates, July 2001. Analyses based on NMEP Community Monitoring Survey January/February 2001; Disenrollee Survey Module in six sites including Sarasota, Tucson, Minneapolis, Houston, Centre County PA, and Nassau County NY.

3.6 Digression on New Enrollees

As part of the monitoring work in 2000 we examined the situation of one particular type of special population — new enrollees to Medicare — through in depth interviews with 31 newly enrolled beneficiaries in two sites (Springfield, MA and Tucson, AZ, both of which have relatively strong local sources of information about Medicare). All of these persons had made their initial Medicare coverage selections within the prior 2-5 months. We did not include any new enrollees covered by Medicaid, because the nature of their choices are different from other enrollees. The interviews explored how the beneficiary decided on which type of Medicare coverage to select and the information sources they used in the selection process. The findings from this assessment are summarized below.

1. As would be expected in a small group, new enrollees varied extensively in terms of their approaches to making this initial coverage decision. At one extreme were beneficiaries who carefully scanned their choices, read materials, and organized individual comparison charts. Even these few beneficiaries, who were so careful about collecting and arranging information, were unaware that local agencies provided already developed comparison charts and personal counseling. At the other extreme were beneficiaries who relied almost entirely on others' advice, such as a man who was unaware that Medicare does not offer comprehensive coverage, had joined a managed care plan after responding to a mail offer, and asked the interviewer, "I just have one question - what does an HMO offer me that Medicare doesn't? Why do I need an HMO?" Another example was a woman who relied almost completely on a "financial advisor" from her church for the best choice, because she has difficulty understanding these kinds of issues — "nobody is good at everything." She had let insurance lapse in the past, and had had to pay out of pocket for unexpected surgery. Her financial advisor suggested a supplemental plan that she was told is "better than AARP (supplement) and he sells it."

2. These new enrollees had different circumstances and related sources of confusion about Medicare. Many persons we interviewed had retired early, and did not have access to group insurance programs for some years (four had no coverage at all for several years). The high prevalence of pre-existing conditions for many has made health insurance difficult to find and to afford, and some of these persons were confused about the implications of pre-existing conditions for access to choices in Medicare, supplemental coverage, and managed care plans. Others are eligible for military and veteran's benefits, but uncertain how these benefits all "fit together". There was also evidence of confusion about how "employer sponsored retiree insurance" fits together with Medicare. One woman, for instance, declined Part B coverage, thinking that the employer coverage would continue to cover such benefits even though she had passed age 65 — and was surprised when her employer notified her that this was no longer the case.

3. Most of the new enrollees we interviewed were not very familiar with Medicare, even though all had made coverage choices. Although a few new enrollees had thoroughly investigated their coverage options, most reported far more limited searches. Many made minimal use of Medicare information sources, with reliance on plans and recommendations from others. Choices were uncritical ones, with limited search activity reported. Most of the people we interviewed sought out recommendations from family or friends who had already been through the process of enrolling and choosing. Such plans were generally contacted and supplied details

without a process of analytical comparison. Many new enrollees who selected managed care plans were not familiar with the costs, benefits, or networks of other plans in the market. For example, a new enrollee in Tucson who was worried because the plan she joined limits prescription coverage to generic medications was unaware that a competing plan does offer coverage for brand name prescriptions. A few enrollees in Tucson were certain that the competing plan had terminated its Medicare product in the area.

4. All of the beneficiaries in our sample reported to have used some information source, such as a broker or managed care salesperson, in addition to a recommendation referral, but use of formal channels appears to be minimal and perfunctory for many. Most remembered receiving the Handbook, but noted they had saved it for future reference. About half reported that they were aware of the 1-800-MEDICAR(E) helpline. Only eight were aware of the local unbiased counseling services (of SHIP-trained counselors); most thought the local Social Security office would be a source of Medicare information, if they needed it. Some of these persons were aware of the possibility of a Medicare web site (“everybody has one now”) but no one had used it for help with their plan decision.

In general, we were somewhat surprised to learn that the new enrollees (at least those without some employer connection) were not unlike other enrollees who have been monitored using the NMEP Community Monitoring Survey. Based on this small and select sample they seem no better informed about Medicare, not substantially more interested in availing themselves of newer technological approaches to providing information (web, helpline), nor more critical and analytical in their decision making activities. Among this segment of enrollees, all (i.e., 100 percent) of whom are being forced to choose, there is both ignorance of the program and the benefits of the available information sources and an overlay of uncertainty about complementary coverage or a worry for the previously uninsured that “I better take the first plan that offers coverage”. Uncritical choosing seems the norm for these new enrollees.

4.0 Use of Information about Medicare by Sub-populations of Enrollees

This section of the report uses data from the NMEP Community Monitoring Survey to examine patterns of Medicare information use by persons in beneficiary sub-populations. These analyses are descriptive and, in some cases, based upon a multivariate standardization procedure as described earlier.²²

4.1 Reported Use Rates and Trends

Table 4.1 describes the proportion of sub-populations who reported using any information source about Medicare during the past year, and the number of sources they mentioned.²³ The latter is an indicator of the intensity of information seeking by beneficiaries. A high majority of the persons in these special sub-populations reported using some Medicare-related information during the last year: generally, about two-thirds to three-fourths of persons in these groups self reported some use of Medicare information in the past 12 months. With some exceptions, persons reported using between one and three sources of such information. The sections below provide more detail on the types of information sought and the channels used.

Across groups, there are differences in the information seeking rates, ranging from a low of 64-65 percent (in the live-alone group, the persons not graduating from high school and the persons who lost a spouse) to a high of about 88 percent (for persons who were involuntarily disenrolled from a plan). Generally, the vulnerable socio-economic groups have lower information seeking rates than the persons who faced acute situations. The new enrollees (all of whom must make a choice) and the disabled beneficiaries are high users of information, with about 88 percent using some source of information during the past 12 months.

The average beneficiary reported using about 1.6 sources of information during the past year. The patterns on this intensity measure are similar to the overall information seeking rate discussed above. The disenrollees and persons whose doctor left a plan are the ones reporting the most information sources. Poorly educated and living alone beneficiaries use the fewest sources. One interesting note is that the ‘other minority’ group (Asians, others) uses a relatively large number of information sources.

²² The companion report by Wilwerding examines patterns of usage of Medicare information more extensively, and tests hypotheses about trends, marginal effects of beneficiary characteristics and differences due to site.

²³ The survey asked about the use (or not) of seven channels of information that might be used to obtain information on Medicare, and asked separately whether three particular types of information were sought (managed care, supplemental, and claims/billing). The first column of data is a constructed variable that captures whether the respondent mentioned using any channel or seeking any of these types of information. If any method or source is mentioned, the respondent is assigned a value of one, otherwise zero. The second column counts the number of sources (including in-person, materials, and other sources) mentioned across the survey questions pertaining to channel and type of information.

Table 4.1
Medicare Information Usage: Annual Period Ending Jan/Feb 2001

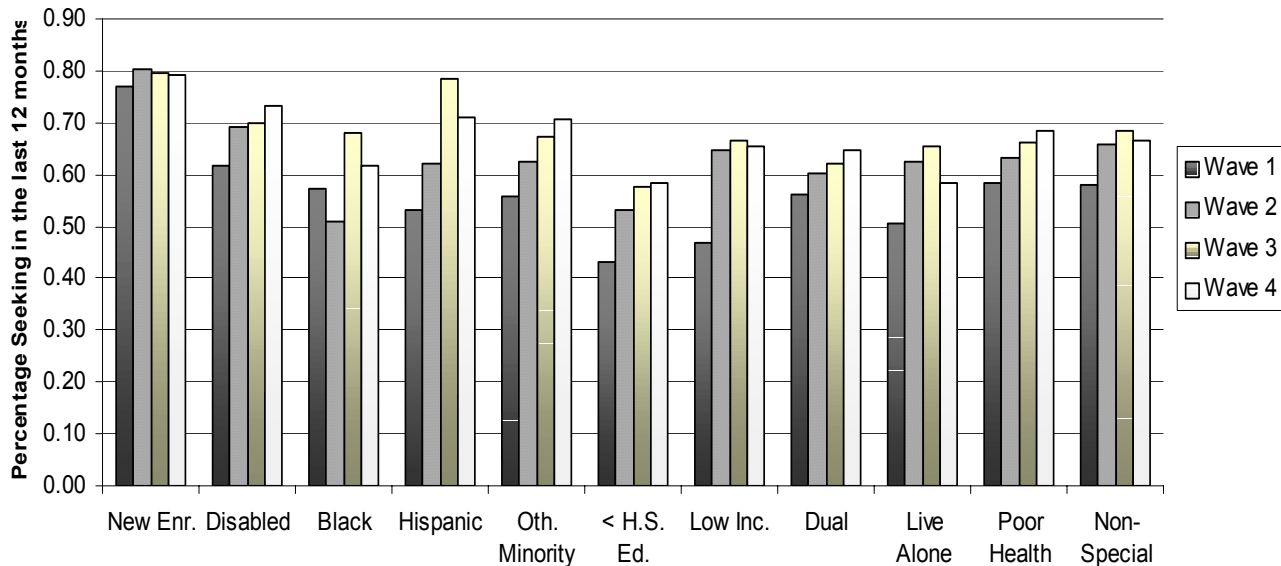
Population	Percent Using Any Information in Past 12 Months	Mean # of Reported Sources of Information per Person
All Beneficiaries	69.1%	1.633
New Enrollees	78.7%	2.892
Vulnerable Segments		
African-American	69.9%	1.388
Hispanics	73.0%	1.904
Other Minorities	73.1%	2.399
Low Income (< 10K)	70.8%	1.541
Less Than H.S. Education	64.2%	1.128
Poor Health	69.4%	1.810
Live Alone	64.7%	1.299
Dual Eligible	70.4%	1.488
Disabled	77.1%	2.091
Situational Segments		
HMO Left Medicare	88.0%	3.617
Physician Left An HMO	81.6%	3.056
Employee Retirement Benefits Changed	76.6%	2.610
Spouse Died	64.8%	1.618
Financial Difficulties	77.6%	2.223
Health Declined	76.3%	1.952

Source: Abt Associates' NMEP Community Monitoring Survey of Beneficiaries. This telephone survey of beneficiaries <86 years old was conducted in January/February 2001 in 10 communities, including Sarasota, Springfield MA, Dayton, Tucson, Olympia, Eugene, Minneapolis, Houston, Centre County PA, and Nassau County NY.

Trends. The general trends in overall usage rates for these sub-population groups are shown in the accompanying Figure 4.1, which shows the proportion of persons in each group that report using Medicare information. Separate bars show this measure for each of the four waves of the survey. The first (darkest) vertical bar represents the wave prior to the mailing of the Medicare handbook in the fall of 1998 — when the handbook was infrequently reported as a source used for information about Medicare. This wave shows relatively low overall information seeking rates for all sub-populations during the prior year. As expected, new enrollees had the highest usage rates, due in part to their receipt of the handbook at enrollment. For reference, the set of bars on the right side of the chart shows trends for the balance of the beneficiary population (persons not included in any of the other groups shown on the chart).

The chart shows indications of positive trends in information use among some of the special populations we study. The only sub-populations not showing a discernable trend are the new enrollees and the African Americans. The latter group shows an inconsistent pattern of usage from year to year. The new enrollees show a pattern of consistently high use of Medicare information, but

Figure 4.1: Trend in Overall Rate of Searching for Sub Populations



Source: Abt Associates' NMEP Community Monitoring Survey of Beneficiaries. This telephone survey of beneficiaries <86 years old was conducted in January/February 2001 in 10 communities, including Sarasota, Springfield MA, Dayton, Tucson, Olympia, Eugene, Minneapolis, Houston, Centre County PA, and Nassau County NY.

no trend. The patterns for the persons with low education, those living alone, and those with low income are somewhat different as well. Here, the large jump in reported usage after the 1998 survey wave is very evident, but subsequent evidence of a trend is quite weak. The persons with less than high school education have the lowest overall usage rates, and though they continue to rise from wave to wave, the rate of increase is declining.

Trend data for the sub-populations with event “situations” is not available for the four survey waves (only two years of data are available for these items) and we do not report it as an indication of trends in information use.

Type of Information Sought. Table 4.2 displays the rates at which sub-populations reported using information on particular Medicare issues. The Community Monitoring Survey asks questions only about three types of issues; claims/eligibility; supplemental insurance; and, HMOs/managed care plans. There are few notable findings to be drawn from Table 4.2 concerning sub-population information use patterns. Overall, about a fourth of the beneficiaries use information about claims/eligibility during a year, about 18 percent use information on Medigap, and about 16.5 percent use information on M+C plans. The low information seeking rates of the less well educated and the live-alone population are evident for all three types of Medicare information. Consistently high rates of information use are also evident for the new enrollees, the disenrollees and other situational users.

The race/ethnic categories have different patterns regarding the type of information channels used, partly reflecting insurance choices. The Hispanics are the heaviest user of managed care information (and they are the most heavily enrolled persons in such plans in this sample), while the ‘other minority’ group is the heaviest user of the billing/enrollment information.

Table 4.2**Special Population Searching for Information on Specific Topics**

(percent of group self reporting use of information on the topic in the past 12 months)

Population	Claims and Billing	Medigap or Supplemental	HMO
All Beneficiaries	24.5%	18.1%	16.5%
New Enrollees	28.4	36.4	32.3
Vulnerable segments			
African-American	27.3	19.1	12.1
Hispanics	32.9	16.5	28.1
Other Minorities	38.4	22.5	23.5
Low Income (< 10K)	23.9	16.7	17.9
Less Than H.S. Education	19.1	13.9	12.4
Poor Health	34.4	22.8	16.4
Live Alone	19.0	16.5	14.1
Dual Eligible	24.6	18.3	17.5
Disabled	35.1	23.0	18.9
Situational Segments			
Own/Spouse HMO Left Medicare	27.9	39.2	45.8
Own/Spouse Physician Left An HMO	30.2	27.2	39.9
Employee Retirement Changed	35.9	23.7	24.3
Spouse Died	24.9	16.7	14.4
Financial Difficulties	33.4	26.5	22.4
Health Declined	30.2	20.6	18.3

Source: Abt Associates' NMEP Community Monitoring Survey of Beneficiaries. This telephone survey of beneficiaries <86 years was conducted in January/February 2001 in 10 communities, including Sarasota, Springfield MA, Dayton, Tucson, Olympia, Eugene, Minneapolis, Houston, Centre County PA, and Nassau County NY.

Channels of Information Used. Table 4.3 shows the proportion of each sub-population that used information by means of particular information channels during the past year. In addition to the fact that high and low use groups are evident here as well (new, disabled, disenrollee, etc.) there are some other interesting patterns. Across every group noted here, there is remarkable consistency in the dominance of the handbook as the most frequently used channel of information. Across sub-populations never fewer than about 4 in 10 beneficiaries used the handbook during the 12 months prior to the survey, and in most groups, the handbook is used more than twice as frequently as the next highest channel. New enrollees and persons involuntarily disenrolled from health plans are the greatest users of the handbook among all the groups, and

Table 4.3**Special population self reported use of particular information channels in Wave 4 (January/February 2001)**

(percent of beneficiaries self reporting use of the information channel in past 12 months)

Population	Handbook	Any 800#	Medicare Helpline	Counselor	Insurance Co. Rep.	Internet	Medicare Web Site	Health Fair
All Beneficiaries	43.0%	16.4%	6.7%	2.4%	10.9%	4.1%	2.4%	7.7%
New Enrollees	55.3	21.2	10.3	4.0	18.7	8.3	5.0	6.3
Vulnerable Segments								
African-American	46.7	14.8	7.7	3.1	5.9	1.3	0.6	5.4
Hispanics	45.6	15.4	2.7	3.4	14.1	2.2	1.7	5.6
Other Minorities	41.3	24.6	13.4	2.8	13.9	3.8	1.4	6.9
Low Income (< 10K)	43.3	17.2	7.5	6.0	8.3	0.9	0.5	7.1
Less Than H.S. Education	39.5	11.7	5.8	2.5	9.4	0.9	0.5	3.5
Poor Health	38.8	23.6	8.0	4.9	8.1	5.1	4.2	5.9
Live Alone	40.8	12.9	5.4	2.8	9.1	2.0	1.3	8.1
Dual Eligible	40.8	12.3	5.4	3.6	12.1	2.4	1.4	7.9
Disabled	46.5	34.2	10.8	4.9	6.9	8.0	5.0	5.1
Situational Segments								
HMO Left Medicare	55.2	20.7	7.9	4.3	33.6	5.5	1.8	12.3
Physician Left An HMO	51.1	21.8	10.4	2.7	19.0	6.5	3.2	11.8
Employee Retirement Benefits Changed	49.0	24.1	11.0	2.7	11.2	7.1	3.9	8.8
Spouse Died	40.1	23.0	10.4	2.3	7.1	3.8	3.7	3.5
Financial Difficulties	46.8	23.6	10.2	6.5	13.4	4.4	2.7	8.9
Health Declined	45.1	19.9	7.6	3.7	12.7	5.1	2.3	8.1

Source: Abt Associates' NMEP Community Monitoring Survey of Beneficiaries. This telephone survey of beneficiaries <86 years old was conducted in January/February 2001 in 10 communities, including Sarasota, Springfield MA, Dayton, Tucson, Olympia, Eugene, Minneapolis, Houston, Centre County PA, and Nassau County NY.

they are also the most frequent users of insurance company sources. Other findings of interest include:

1. The Disabled and New Enrollee groups are the highest Internet users among the sub-populations, with about 8 percent of each group using the Internet for finding Medicare information annually. The Medicare Internet site is also most frequently used by these two sub-populations, with about 1 in 20 persons in these groups using www.medicare.gov annually.
2. Persons who faced situations of involuntary disenrollment or who had a physician who left a plan are distinctive in their use of information channels. They are the most frequent users of health fairs (about 12 percent of these groups attended one) and the most frequent users of insurance company channels (19-34 percent used them during the year).
3. Helpline use is highly variable across the sub-populations we study. The disabled group is the highest helpline user group (over a third called a helpline during the year). “Other” minorities rely heavily on helplines to get information, as contrasted with the African Americans and the Hispanics.

Sources of Information. Table 4.4 describes the sources of information used by beneficiaries for questions pertaining to resolving issues about claims/eligibility (a), supplemental insurance (b), and HMOs (c) respectively. The column percentages do not add to 100 percent because multiple sources are possible for persons who said they sought a particular type of information during the past year. Bearing in mind that the sample sizes are quite small in some instances, the main generalizations from these tables are:

1. Patterns of information source usage vary considerably across type of information sought (claims, Medigap, HMO).
2. Generally, across types of information sought, new enrollees are much more reliant on the handbook than other groups---the handbook is far and away the leading source of information for new enrollees seeking information on claims, supplemental coverage and HMOs.
3. Disabled beneficiaries also rely on the handbook, tend to use SSA as a source more frequently, and tend to use a broader set of sources than the other beneficiary sub-populations.
4. “Other” minorities (primarily Asians) tend to use the handbook less and rely more heavily on family and friends.
5. Most of the Internet use appears to be from new and disabled beneficiaries.
6. For information about Medigap insurance and managed care plans, insurers and plans are the most mentioned source other than the Handbook.

- 7. For managed care information, many of the studied sub-populations rely heavily on information from family, friends and physician offices for information.**

Table 4.4**Special Population Use of Sources of Information about Claims, Medigap, and HMOs**

(Percent of sub populations who sought information of a particular type (Claims, Medigap, HMO), who reported using a particular source)

Sources	New	Disabled	Blacks	Hispanics	Other Minorities	Less than High School education	Low Income	Dual Eligible	Lives Alone	Poor Health
Sources of Information about Claims										
Talked to a family member or friend	0	8%	0	10%	22%	14%	0	5%	8%	7%
Talked to someone at the MD office	0	23%	23%	0	22%	21%	17%	22%	25%	32%
Talked to someone at AARP or senior org	0	14%	6%	0	5%	3%	8%	3%	6%	0
Talked to someone at SSA	9%	20%	0	0	5%	3%	0	3%	8%	0
Talked to someone at a Helpline	25%	26%	15%	22%	15%	15%	23%	11%	11%	17%
Talked to a plan or Insurance Rep	17%	7%	7%	5%	17%	11%	4%	9%	8%	13%
Medicare Handbook	72%	63%	60%	63%	44%	56%	71%	52%	58%	68%
Internet Sources	17%	12%	5%	0	7%	3%	4%	3%	6%	3%
Sources of Information about Medigap										
Talked to a family member or friend	15%	6%	8%	0	7%	12%	11%	10%	18%	21%
Talked to someone at the MD office	6%	15%	8%	0	0	8%	6%	15%	18%	8%
Talked to someone at AARP or senior org	15%	15%	0	9%	7%	0	6%	3%	11%	8%
Talked to someone at SSA	0	11%	0	0	0	0	0	3%	0	0

Table 4.4 (continued)**Special Population Use of Sources of Information about Claims, Medigap, and HMOs**

(percent of sub populations who reported using a particular source)

Sources	New	Disabled	Blacks	Hispanics	Other Minorities	Less than High School education	Low Income	Dual Eligible	Lives Alone	Poor Health
Talked to someone at a Helpline	22%	9%	8%	8%	8%	17%	16%	3%	9%	48%
Talked to a plan or Insurance Rep	32%	15%	21%	31%	28%	16%	8%	21%	23%	27%
Medicare Handbook	65%	69%	57%	54%	52%	63%	57%	50%	59%	55%
Internet Sources	18%	26%	0	0	8%	2%	3%	3%	5%	5%
Sources of Information about HMOs										
Talked to a family member or friend	36%	11%	0	0	29%	16%	19%	24%	13%	8%
Talked to someone at the MD office	27%	27%	11%	0	33%	16%	32%	21%	21%	8%
Talked to someone at AARP or senior org	2%	0	0	0	9%	16%	7%	21%	10%	0
Talked to someone at SSA	13%	20%	11%	14%	9%	6%	13%	9%	13%	0
Talked to someone at a Helpline	27%	10%	6%	0	3%	9%	9%	3%	5%	5%
Talked to a plan or Insurance Rep	29%	23%	11%	35%	33%	26%	9%	27%	21%	30%
Medicare Handbook	67%	58%	44%	35%	42%	52%	56%	48%	59%	35%
Internet Sources	12%	19%	11%	9%	9%	2%	3%	3%	6%	0

Source: Abt Associates' NMEP Community Monitoring Survey of Beneficiaries. This telephone survey of beneficiaries <86 years was conducted in January/February 2001 in 10 communities, including Sarasota, Springfield MA, Dayton, Tucson, Olympia, Eugene, Minneapolis, Houston, Centre County PA, and Nassau County NY

4.2 Statistical Estimates of Differences in Use Rates of Information

The annual use rates of information by the sub-populations were examined using a model that controls for age, gender, site and year. Table 4.5 contains the results. The data is taken from six cities, for the NMEP Community Monitoring surveys conducted in Jan/Feb 2000 and Jan/Feb 2001.

Two information usage measures are examined here. The first is simply whether or not the beneficiary used any information on Medicare during the year. The second measure is whether or not the beneficiary used any information other than the *Medicare & You* Handbook. This latter measure is used because of the dominant role of the handbook in information seeking behavior, and the need to understand if there are patterns relating to the other channels, taken as a set. The coefficients in the table show the difference between the sub-population and all other beneficiaries in terms of the fraction of these persons who used Medicare information during the year. For example, the percent of new enrollees who use information during the year is about 8.7 percentage points higher than other beneficiaries, controlling for age, gender, site and year. African-Americans, on the other hand, have information usage rates that are essentially no different than other beneficiaries.

Table 4.5
Significant Differences in Medicare Information Usage Rates by Sub Populations

Population	Percentage Point Difference in Information Use Rate during the past 12 months relative to other beneficiaries	Percentage Point Difference in Information Use Rate from sources other than the Handbook during the past 12 months relative to other beneficiaries
Average Information Use Rate for All Beneficiaries	66.7%	45.6%
New Enrollees	8.7 **	10.9 **
Minorities		
African-American		
Hispanics		
Other Minorities		6.3 *
Other Vulnerable		
Low Income (< 10K)		
Less Than H.S. Education	-4.9 **	-8.4 **
Poor Health		
Live Alone		-4.6 **
Dual Eligible		
Disabled	8.1 **	17.4 **
Situational Segments		
HMO Left Medicare	13.5 **	20.7 **
Physician Left An HMO	11.6 **	18.6 **
Employee Retirement Benefits Changed	8.7 *	13.4 **
Spouse Died		
Financial Difficulties	7.6 **	12.3 **
Health Declined	5.3 **	7.1 **

Source: Abt Associates' NMEP Community Monitoring Survey of Beneficiaries conducted in Jan/Feb 2000 and Jan/Feb 2001 in Sarasota, Springfield MA, Dayton, Tucson, Eugene, Olympia. Estimates obtained from weighted

regression model adjusting for age, gender, site and year. The table shows differences that were statistically significant. $p < .05$ () $p < .01$ (**)*

There are several findings of significance in these data.

Sub-populations of persons with acute situational needs for information have much higher information usage rates. Beneficiaries appear to react to specific, immediate situations to search for information. These situations take the form of events in their lives and in insurance markets. Among the six situations we were able to examine, only one, persons whose spouse died, did not show a significantly higher information usage rate. To illustrate, for the persons whose physician dropped out of the health plan they were enrolled in (about 9-10 percent of all beneficiaries we surveyed), about 77 percent of them used some Medicare information during the year — among their counterparts, only about 65 percent used information during the year (the adjusted difference shown in Table 4.5 is 11.6 percentage points). The gap in usage for these persons is much larger if the use of the handbook is ignored. For sources of information other than the handbook the information usage rate is nearly 19 percentage points higher for persons experiencing a physician drop out from a plan than for other beneficiaries.

These differentially high information usage rates for persons who faced acute situations are generally higher for the non-handbook channels of information. For example, for involuntary disenrollees, usage rates for all sources are about 13.5 percentage points higher than usage rates for other beneficiaries. But for sources other than the handbook (the second column in the table), the information usage rates for this group are about 20.7 percentage points higher. This pattern is evident for all situational groups except for persons whose spouse died.

New enrollees and Disabled beneficiaries are more frequent users of Medicare information than their counterparts. Over the four cycles of the survey, new enrollees and disabled beneficiaries consistently search for information at rates much higher than the other age groups. Like the special situation sub-groups, the use rates of information for the disabled population are also much higher for non-handbook sources (the difference between Disabled and non-Disabled persons is more than twice as large for the measure of usage other than the handbook). New enrollees, on the other hand, have about the same elevated usage rates (relative to other beneficiaries) for the handbook as for non-handbook sources.

Ethnic and racial minorities do not appear to use more or less information than their counterparts. There is even some indication of a higher usage rate for the ‘other minorities’ for non-handbook sources (6.3 percentage points).

Poorly educated persons, as a group, use less Medicare information. There is also an indication that the persons living alone use non-handbook sources of information less frequently than other beneficiaries.

In summary, these data suggest that as a group, persons facing Situational Events pertaining to their health care and health insurance use Medicare information more frequently than other groups of beneficiaries. The event of spousal death is the exception for situations we studied. The vulnerable sub-groups of beneficiaries, on the other hand, are not consistently high or low users of information. Particular sub-groups such as persons with low education are low users of information, and the disabled are consistently high users. New enrollees are also high users.

Not all persons with acute information situations used information about Medicare. An addendum to this analysis concerns the fact that not all beneficiaries facing important situations actually use information about Medicare. For involuntary disenrollees, as an example, about 88 percent used information during the year. What about the others? We conducted two focus groups of such persons (disenrolled non users) and determined that some persons had others in the family who became informed, and other persons actually sought information, but perceived it not to be included in the questions posed by the survey. But still many others had no good explanation for the non-using behavior. Using the survey data, we profiled the disenrollee “users of information” against the profile of their counterparts who said they did not use. The results are reported in Table 4.6. Compared to disenrollees who did use information, the non-users tended to live alone, have less education, more often minority and in poorer health than the disenrolled beneficiaries who sought information. These same factors typically distinguish users of information from others.

Table 4.6
Profiles of Disenrollees Who Used and Did Not Use Information

Population Group	Disenrollee Users of Information	Disenrollee Non Users of information
Age	72.7%	73.8%
Male	47.3	40.9
Married	70.0	54.6
Live alone	24.6	36.4
White	81.8	72.7
African American	9.1	4.6
Hispanic	2.7	9.1
Other Race	4.6	4.6
Less than HS Diploma	19.9	27.3
HS	30.1	36.4
More than HS	50.0	36.4
Makes own Decisions	82.2	78.2
Has Employer Coverage	25.0	39.1
Dual eligible	20.2	34.8
Good Health	82.7	59.1
Fair	12.7	27.3
Poor Health	3.6	9.1

Source: Abt Associates' NMEP Community Monitoring Survey of Beneficiaries conducted in January/February 2001 in ten sites including Sarasota, Springfield MA, Dayton, Tucson, Eugene, Olympia, Minneapolis, Nassau County NY, Centre County PA, and Houston.

5.0 NMEP/REACH and Information Suppliers' Activities Regarding Sub-populations

Site monitoring in six cities over the last 30 months has provided an opportunity to understand how information about Medicare is supplied in local situations. This chapter of the report describes the activities as they pertain to sub-populations of the Medicare population. The sites we have been monitoring include:

- Dayton, OH;
- Eugene, OR;
- Olympia, WA;
- Sarasota, FL;
- Springfield, MA; and
- Tucson, AZ.

In each of four waves since Fall 1998, we conducted expert interviews with contractors, SHIPs, local organizations, some plans and providers. Focus groups and interviews with beneficiaries were also done.

5.1 Site Infrastructure for Supplying Medicare Information to Special Populations

Our monitoring activities revealed considerable variation in the situation of localities regarding Medicare information supply. At all sites, beneficiary information and education is provided on a limited basis by traditional Medicare information suppliers (carriers, fiscal intermediaries, Peer Review Organizations, and SHIPs). Some Medicare information is also provided by local service organizations such as senior centers, government agencies, Area Agencies on Aging (AAAs), hospitals, managed care and other providers, and by congressional office staff. These organizations typically provide seniors or other constituents with other kinds of information and services, and periodically use their access to these persons to provide information about Medicare.

Our primary observation about local information supply is that at the local levels, special populations are not now a primary focus of information suppliers. Most organizations in the sites we monitored do not have a systematic approach or strategy for targeting special populations and the community organizations (e.g., housing, church, community organizations), if any, that may serve them. With few exceptions, Medicare information suppliers at the six monitored sites have not directed Medicare information and activities to special population groups. At some sites, even information for general beneficiaries is not widely apparent. Community-based organizations serving special populations typically operate independently and apart from mainstream Medicare information suppliers, particularly those organizations that serve Communication Difficulty and Vulnerable Segments that may be further distanced from mainstream networks by cultural and language barriers, rural or remote residence, or disability status. Table 5.1 below summarizes the activities pertaining to special populations in the six sites we monitored. Sites such as Tucson and Springfield, MA appeared to have more

coordinated programs of Medicare information supply for general beneficiaries, were better resourced, and were directed by strong organizational leader/advocates who have taken some

Table 5.1 Site Information Infrastructure for Medicare Special Populations: Summary Characteristics, 2000				
Site	Special Populations Identified by Local Respondent Organizations*	Community Information Infrastructure for Special Populations	Information Activities for Special Populations (Primary Audiences)	Information Activities for Intermediaries & Partners (Secondary Audiences)
Dayton, OH	<ul style="list-style-type: none"> - African Americans - Hispanic/Latino Americans - Near retirees (GM plant and other employers) 	Decentralized, relatively uncoordinated set of information suppliers; limited special populations materials, little information or activity observed for special populations. African American population largest identified target group, limited information provided through independent community center.	Limited if any outreach, information, activities for special populations. Most organizations provide small-scale presentations or demand-focused information by phone or in person. Little or no activity observed targeted to African American or other special populations.	No inter-organizational linkages, outreach observed involving mainstream information providers and community organizations serving special populations. No direct RO participation in local special populations activities.
Eugene, OR	<ul style="list-style-type: none"> - Hispanic/Latino Americans - Native Americans - African Americans - Rural residents - Disabled individuals - Low income 	Some coordination among information suppliers; some special populations materials, activities; Rural, Hispanic/Latino populations largest identified groups; various community organizations serve special populations on a limited basis.	Limited outreach, information, activities for special populations. Most organizations provide demand-focused information by phone or in person, general events at senior centers; rural senior centers most prominent outreach venue for special populations; little or no activity observed targeted to African American, Native American, disabled communities.	Limited inter-organizational linkages, outreach observed involving mainstream providers and orgs. serving special populations. Small community-based orgs. Serving special populations (disabled, vision-impaired, tribal) address general ethnic needs, report limited access to Medicare information, but do refer to 3 primary information suppliers on an as-needed basis. No RO role in local special populations activities.
Olympia, WA	<ul style="list-style-type: none"> - Hispanic/Latino Americans - Asian & Pacific Islanders - Disabled individuals - Veterans - Russian refugees/immigrants - Low income - Rural residents - Non and limited English speakers 	State SHIBA with local affiliates serve as the central information source for general and special populations; most suppliers refer to SHIBA; emerging infrastructure and some materials for special populations. Low numbers and limited organization of targeted special populations.	Limited but developing outreach, information, activities for special populations. Most organizations refer to state and local SHIBA.; in the area bilingual counselors available in Spanish, 4 Asian languages, ATT language line used; demand-focused information by phone or in person as well as some limited direct outreach, activities. Some materials, translated materials developed by SHIBA and NAPCA (API languages). SHIBA Disability Work Group conducts monthly conference calls. -SHIBA conducted 'clinics' in area -Disability Work Group monthly calls -Group Health Cooperative Senior Forum meetings; Spanish materials for members; prescription drug discounts, -Outreach, activities for Filipinos in surrounding areas	Moderate, developing inter-organizational linkages from established mainstream information network developed by state SHIBA., as the central information referral source. SHIBA outreach to community organizations serving special populations to provide training, information for dissemination by local special population groups. RO support to and collaboration with Asian Pacific Islander partners and communities in nearby Seattle metropolitan area.

Table 5.1 (continued)**Site Information Infrastructure for Medicare Special Populations: Summary Characteristics, 2000**

Site	Special Populations Identified by Local Respondent Organizations*	Community Information Infrastructure for Special Populations	Information Activities for Special Populations (Primary Audiences)	Information Activities for Intermediaries & Partners (Secondary Audiences)
Sarasota, FL	<ul style="list-style-type: none"> - Hispanic/Latino Americans - African Americans - Disabled individuals - Dual eligibles 	Few Medicare information suppliers, with no coordination; limited special populations materials, no information or activity observed in 2000 for special populations other than 1 non-renewal meeting for Spanish-speaking disenrollees. Low numbers and limited organization of targeted special populations.	Little or no outreach, information, activities for special populations. SHIP and senior center host agency provide limited, demand-focused information by phone or in person. No activity observed targeted to African American, Hispanic or other special populations in 2000 (other than 1 non-renewal meeting to Spanish-speaking disenrollees).	No inter-organizational linkages, outreach observed involving mainstream information providers and community organizations serving special populations. No direct RO participation at the site regarding special populations; one renewal event for Spanish-speaking disenrollees involved a key partner (PRO).
Springfield, MA	<ul style="list-style-type: none"> - Hispanic/Latino Americans - African Americans - Vietnamese immigrants - Russian immigrants - Disabled individuals - Frail elderly/homebound - Low income 	Informal local coordination among information suppliers; emerging information, materials for identified special populations through local SHIP/Council on Aging, one ethnic organization providing some information to Hispanic/Latinos.	Limited but developing outreach, information, activities for special populations. Most information, outreach provided by SHINE and Spanish American Union; bi-lingual SHINE counselor, Spanish summary in general senior newsletter (Russian and Vietnamese sections, and direct mailings to African Americans planned). -Newsletter for seniors (circulation 24,500) including Spanish summary section; plans for Russian and Vietnamese sections, direct mailing to African Americans (Springfield SHINE/DEA) -SHINE counselor co-locates at Spanish American Union for Hispanic/Latino services.	Moderate, developing inter-organizational linkages from established mainstream information network developed through regional/local healthcare coalition, with SHINE as the central information referral source. SHINE outreach to limited English-speaking sub-groups. No direct RO participation in local special populations' activities.
Tucson, AZ	<ul style="list-style-type: none"> - Hispanic/Latino Americans - Native Americans - Disabled individuals 	Local SHIP (sponsored by AAA) serves as recognized lead information provider for general Medicare population, and some coordination with AARP and Intertribal AAAs (Native American initiative in neighboring area) coordinated by Arizona Beneficiary Coalition; limited information, materials available for Hispanic/Latinos as largest identified target group; overall special populations information limited.	Limited outreach, information, activities for special populations. SHIP has part-time bi-lingual (Spanish) staff member. Some activities for large Hispanic/Latino community, including information and marketing activities by managed care organizations; limited Spanish language materials. Some activity reported to target disabled community. Some information activities provided by nearby Inter-tribal AAA for Native Americans in surrounding areas. -Public benefits, health information, activities for Native Americans through AAA and state, AARP; some publications available; use of nearby IHS hospitals. -Managed care marketing, outreach, activities targeted to Hispanic/Latinos with mixed success.	Limited inter-organizational linkages, outreach observed involving mainstream providers and community organizations serving special populations. Managed care organization marketing occurs independent of mainstream information networks. Hispanic/Latino information networks described as largely interpersonal, community-based. Disabled community not well integrated with general or special Medicare information intermediaries, networks. No direct RO participation in local special populations activities, other than reported media buys on one Hispanic newspaper. (Most RO special population outreach activity in state focused in Phoenix area.)

*These were identified as local notable sub-populations, though there may or may not be any special information activities underway. The special populations targeted by the CMS Regional Offices appear in a subsequent table.

Source: NMEP Monitoring Case Studies conducted by Abt Associates from Fall 1998 to Spring of 2001 in Sarasota, Springfield MA, Dayton, Tucson, Eugene, and Olympia.

initiative to develop special population information and outreach. While actual numbers and efforts directed to special populations at these sites are still limited, Tucson and Springfield (as well as statewide activity in Olympia) reported somewhat more types of activity for special population sub-groups than our other monitored sites. Sites like Sarasota and Dayton show less coordinated supplier activity in providing Medicare information to general beneficiaries as well as for special populations.

In Springfield and Tucson Medicare information is provided mainly through informal networks with the local SHIP/Council on Aging serving as the central Medicare information supplier at the local level. Springfield's local SHIP (SHINE) is the lead Medicare information supplier in the community; virtually all organizations say they received information through SHINE. SHINE has staff counselors who speak Spanish, Vietnamese, and Russian. The Spanish American Union (SAU) provides some information to Hispanic/Latino beneficiaries in the Springfield area, but reports that it is not closely affiliated with mainstream information providers. In Tucson, the local Ship organization (Pima Council on Aging) is the recognized central Medicare information supplier. The El Rio Health Center provides some information to Hispanic/Latino beneficiaries, with a number of educational sessions held routinely at Latino community sites using Spanish translators. However, it appears that these activities are not closely coordinated with mainstream information suppliers.

Dayton, OH and Sarasota, FL are sites with the least developed information networks and the most limited information outreach and activity for special populations of our six sites. These sites provided only basic, demand-focused information for general beneficiaries. Special populations were not a focus of their efforts and awareness of their presence and needs was often absent

As with the other four sites, limited evidence of coordinated general Medicare information and for special populations is seen in the Eugene and Olympia sites. Mainstream community service providers are the primary information sources for general beneficiaries as well as special populations. Information is available to some special population sub-groups in Eugene (such as rural beneficiaries) through small community-based providers on a limited basis. We observed little evidence of inter-organizational coordination among suppliers. In Olympia, Washington's state capital, the state and local SHIBA serve as the principal referral source for Medicare information for all local beneficiary groups.

Sites vary in terms of their level of sophistication and concern with special population information needs and resources for targeting and delivering information to special populations remain undeveloped at most site. At several sites mainstream information providers were unaware of special information populations for Medicare. Some remarked that these populations are "invisible," especially in Communication Difficulty Segments in suburban and limited English-speaking communities. One respondent in Eugene, OR acknowledged difficulties identifying Hispanic/Latino beneficiaries for Medicare information and outreach, noting:

"There are not many Spanish-speaking seniors who are eligible for Medicare. The Hispanic population is mostly young people and young families. Centro Latino says that seniors are a 'hidden population' taken care of by family members themselves."

Suburban and rural areas where special populations are few in number pose particular challenges for information outreach. In suburban Olympia, WA, an advocate for Asian and Pacific Islander communities explained:

“Elders are not ‘visible’ and concentrated, and [Asian immigrants] speak many languages...so most agencies can’t do outreach. In the suburbs [Olympia], many non-English speaking folks are invisible. No one knows how many there are. That’s why we work with community-based organizations. And there are no resources to do it in Thurston County, because it’s a suburb.”

The National Asian Pacific Islander Center on Aging (NAPCA) in nearby Seattle reported working with radio stations and neighborhood groups to reach Filipino elders in Seattle’s King County, but noted that not much information got to Olympia’s Thurston County. Lack of organization and small numbers contribute to difficulties providing outreach and information to these beneficiary groups.

“In places like Olympia there are small pockets of Asian Americans, often not enough to form organizations...many ‘invisible’ and not connected. They need an organizer. There may not be enough to form an organization. No one can talk about an across the board campaign to these populations.”

Mainstream information suppliers are often not widely known or used by populations with special information needs. At our Dayton, OH site mainstream information suppliers reported holding a health fair for African American seniors. But, a respondent from Dayton’s only African American senior center, when asked about her perceptions of the event, knew nothing of the event. In Sarasota, we observed no special populations outreach in 2000 other than a non-renewal meeting for Spanish speaking disenrollees. Following the format of a session held for general beneficiaries last year, a planned Spanish language forum featured the same panelists, assisted by a Spanish interpreter. Local organizers were cautiously optimistic in projecting attendance, as the center is not widely known in the Hispanic/Latino community. The respondent also noted surprise that, while the senior center had 133,000 visits and 12,000 case management hours in 2000, many mainstream beneficiaries at their presentations have not heard of the center. We were told that, *“There are new people moving in, but also some long term residents who are not aware of the center and the services it provides.”* This respondent has spoken at trailer parks located ten minutes away from the center and discovered seniors who have lived in Sarasota for 20 years who were unaware of it.

At the Spanish American Union in Springfield, MA our respondent told us no one had approached the organization about providing Medicare information to special populations. The respondent stated she does not know of other organizations that have Spanish information readily available for beneficiaries the way SAU does. SAU staff have not received formal training about Medicare through the agency, although our respondent, who is also a volunteer counselor at SHINE, reported having attended a seven-day SHINE (SHIP) training when she first became a SHINE volunteer. Since then, she has attended monthly SHINE meetings and has been tested on “new information” every two years. SAU apparently has not been encouraged by state or national affiliates to do more Medicare information activities. Our respondent reported that she relies on SSA and SHINE to provide her with the bulk of her information, but there has been no teaming across organizations to organize activities and education outreach. She did say that this year she felt more *“in the loop”* with other information suppliers, which work as a team, however.

The Washington SHIBA director addressed this issue directly, linking demand for information to awareness of information availability and supply. When we questioned the relatively low demand for Medicare information we observed in Olympia to date, she explained:

“You don’t supply information without doing outreach. The issue isn’t DEMAND but SUPPLY. We weren’t doing a good job of outreach, people didn’t know they could come to us, they probably didn’t know they needed it! We weren’t supplying much outreach, so we weren’t generating much demand.”

Most local suppliers reported that their Medicare information was “available to anyone who requested (demanded) it,” and did not distinguish or target beneficiaries with special information needs. Across our six monitored sites Medicare information to special populations is generally provided only on demand--over the phone or through walk-in counseling sessions through mainstream Medicare providers and information suppliers. However, most mainstream organizations receive few requests for information from special populations, leading some to report that the needs of these groups appeared to be met.

We observed little evidence that RO-defined special population targeting had been implemented locally at the sites we monitored. Identification of target groups appears to be demand oriented, reflecting local perceptions of need and availability of resources at the community level. We did not observe much evidence of secondary segmentation (e.g., proactive, reactive and passive information seeking) of special population sub-groups at our local sites, though Springfield does some outreach for frail elders.

Identification of special populations for outreach at the local level continues to be a problem in many of the sites we monitored. A staff representative in Region 10 (WA, ID, AK and OR), where Latino beneficiaries have been identified as a special population for Medicare information, noted the absence of a CMS resource data base for the Region and described his efforts to develop a Latino senior organizations data base to establish potential partners for REACH activities and events. To create this database, he contacted Latino radio stations and looked up senior services in the phone book. This effort was a necessary step in planning outreach. He explained:

“Traditionally, major partners do not have the ability to work with the Latino population and are reluctant to become involved.”

At the Olympia site, one of the few sites reporting efforts directed to special population groups, the state SHIBA assists local SHIBA affiliates in targeting their activities using a Community Identification process.

“We drill down in levels to see where do people go in the community for information. For Asians it may be elders, low income it could be local clinics or the fruit stand, disabled have their own groups for conditions such as AIDS, MS. Sometimes we train these groups...We can’t assume what works for the mainstream works with these populations.”

Most community organizations and information networks in the sites we monitored do not have staff or resources to adequately address special population concerns, especially when language barriers exist. Some information providers report having one or more part or full time staff with some bilingual capability, but most receive few requests for information and fewer still reach out to local leaders and organizations in these communities. CMS's support is important in meeting suppliers' needs for information and distribution to these audiences.

Across the sites, developing awareness of and activities for special populations seems to be a process that appears to involve considerable time and effort, often evolving over several years as organizations and information networks mature. Sites appear more active when they have one or more lead organizations with strong, aware Medicare information leader/advocate(s). This enables mobilization of resources and support at the local level and promotes proactive collaboration, partnering, and segmentation of information materials and activities to support special populations and their information needs. And, sites tending to be less developed across these dimensions reported more limited awareness of special populations and their needs, and more passive, demand-focused response regarding information outreach and activities. Sites with well-established information dissemination to mainstream beneficiaries also appear more likely to reach out and expand their programming for special populations.

5.2 Developing Infrastructure for Special Populations at the Local Level: Lessons Learned from the Washington State SHIBA

Developing community-based Medicare information infrastructure for special populations is difficult and time consuming, even at mature, well-funded sites. Several special population segments have been identified for Medicare information and outreach. While whites are the overwhelming majority in Washington State, SHIBA has done an increasing amount of outreach to special populations over the past eight years—six of which were spent coming up the learning curve and training — with a truly concerted effort over the past two years.

“Eight years ago we started. It took us 6 years to figure it out. In the last two we’ve become good. Now we know what we need to do. For example, we had a problem with our computer reading Chinese characters. We need to buy a new one, not fiddle with software—the new computers do read Chinese. Translation is another thing. Now I understand when we go to the Spanish community with English stuff we’re insulting them, we’re creating a barrier. Translation isn’t simple. There’s not a direct, literal translation in most other languages. It’s a process. Translate the materials, send them to a team for review, make changes. It’s more than I understood at first.”

SHIBA's commitment to special populations has taken the form of dedicated staff positions, a commitment to diversity in hiring, development of special materials for outreach, and outreach to community organizations serving a range of special population groups. It has also involved a coming to awareness of SHIBA's leader.

“My staff helped me to understand. I’ve become a better person because of all of this, coming to understand how others view things and how important it is to approach people the right way. Just as important as it is in approaching, differently, the middle class

American white woman down the street...No one else is doing it [reaching out to these groups].”

According to a respondent from NAPCA in nearby Seattle, leadership in key organizations is critical to successful inclusion of special populations in information and service initiatives. Describing NAPCA’s experience building bridges with mainstream information suppliers for outreach to API communities, this respondent reported:

“We did lots of partnering with SHIPs, but success was very variable because leadership of the SHIPs is variable. Maybe only 5 SHIPs we worked with in 3 years! (NAPCA works in 10 communities and 8 states, and provides information nationally.) At first they were not at all interested.

“...In communities with sustained outreach efforts [to these groups] for 3 or more years, real gains can be made. Without this effort, no... just doing booklets is not enough.”

In our site monitoring work we observed some efforts by mainstream suppliers to increase their capacity or capability by hiring bi-lingual, bi-cultural staff. But organizational support and a commitment of resources for materials and outreach are also needed to develop sustainable information programs. One respondent at NAPCA explained:

“Being successful in this work takes two sets of skills: 1) language skills, and 2) community organizing skills. You need leadership, mentoring, encouragement to make these efforts work. It takes lots more effort to build bridges that have good foundations.”

The SHIBA also acknowledged these challenges and has taken steps to address the staffing needs and organizational supports required for outreach to special populations. The state organization now has on staff a woman who is fluent in four Asian languages who “*can do the same Medicare outreach we do with middle American English speakers, in these languages.*” SHIBA has worked with community people in a variety of ways and places, with particular efforts targeted to Filipinos during 2000. SHIBA has also established a Disability Work Group that meets by conference call once a month. For non-English speakers in languages spoken by smaller numbers of beneficiaries, SHIBA uses the ATT language line, and reproduces and translates documents.

5.3 Materials and Related Problems for Special Populations

5.3.1 Medicare Materials for Special Populations

Three years into the NMEP campaign, the content and format of NMEP materials and activities continues to focus principally on the general Medicare population and disenrollees, with some translated materials. While this information appears to be widely available and distributed, information for special populations continues to be limited. But distribution is increasing at the six monitored sites, and among interviewed partners, and materials and resources are more evident in observed REACH activities and events.

Due to the generally limited availability of information and social marketing for various sub-groups, materials produced by CMS’s Central and Regional Offices for Communication Difficulty Segments are shared widely across states and regions when they are known to be

available. Asian language materials produced for CMS by NAPCA are also being used nationwide by beneficiaries, family members and other information intermediaries as brochures that can be downloaded from NAPCA's website.²⁴ State partners report collaborating and sharing information such as audiotapes for vision-impaired beneficiaries. Media, including ethnic press and radio in particular, is being used increasingly as an approach for reaching cultural/ethnic audiences. Presentations and workshops for beneficiaries affected by plan non-renewals comprise the majority of NMEP/REACH materials and activities for Situational Segments; non-renewal events were a REACH priority in 2000. Our monitored sites reported limited availability of materials and activities for Vulnerable and Special Opportunity Segments; state partners reported several new approaches to information content and format, including use of cups, placemats, and other giveaways for passive and reactive information seeking beneficiaries in these sub-groups.

Table 5.2 provides a summary overview of Medicare information, materials, and activities for special populations and general beneficiaries.

Table 5.2
Information Materials and Activities for Special Populations*

Abt Source	Communication Difficulty Segments	Situational Segments	Vulnerable Segments	Special Opportunity Segments	General Medicare Population
Site Monitoring Activities in Six Sites	-translated print materials and inserts(from CMS CO) -bilingual counseling -website access for partners	-plan withdrawal presentations and workshops	-brochures developed for low income beneficiaries		-phone, in-person counseling -help-line -presentations -health fairs -website -newsletters -print material -radio -HMO marketing
State/Regional Partnering Study	-production and distribution of audio tapes for vision impaired -production of videos for Native peoples	-plan withdrawal presentations and workshops	-targeted van tours -faith-based presentations -targeted health fairs, expos -placemats for homebound delivered meals	-adult child/grandchild presentations at high schools, universities -collaboration with employers -joint presentations with VA for veterans	-phone, in-person counseling -help-line -presentations -health fairs -website -newsletters -print material -radio -TV -HMO marketing -van tours
REACH Assessment	-radio, call-in shows	-plan withdrawal presentations and workshops	-targeted van tours -targeted health fairs, expos		-phone, in-person counseling -presentations -health fairs -website -newsletters -print material -radio -TV

²⁴ One REACH event we observed yielded very positive feedback on these materials.

Table 5.2
Information Materials and Activities for Special Populations*

Abt Source	Communication Difficulty Segments	Situational Segments	Vulnerable Segments	Special Opportunity Segments	General Medicare Population
					-HMO marketing -van tours

Source: Abt NMEP/REACH Monitoring Activities, 2000.

While translated materials are becoming more available in local sites and at events, simply translating materials into other languages is likely to be inadequate to address the problems of linguistic minorities.

Increased availability of translated materials is due, in part, to CMS-funded efforts. However, linguistic minorities often require materials and approaches that address basic health literacy and content beyond mere translation of information about Medicare in more or less the same fashion that it is made available to mainstream populations. And, proper translation of technical terms about Medicare is often difficult; native terms for many health insurance concepts do not often exist; word by word translations do not often convey the intended meaning due to cultural context differences.

Overall, CMS's efforts to provide translated materials have been greatly appreciated and have been made available by mainstream providers and special population sub-groups when they are aware of these resources. In Asian and Pacific Islander communities CMS-funded efforts have supported development of a series of health booklets in eight languages (on NAPCA's website) and demand in the Asian community is high. We were told:

"There's unquenched demand for Medicare information in the Asian communities. It's a no-brainer working with Asian Community Based Organizations (CBOs). But in other organizations, there's not demand."

According to another site contact, the availability of Medicare information in Asian languages "raised elders' and Asian CBO's expectations. Demand for information increased exponentially over this three-year period." However, efforts to promote information and outreach through mainstream information suppliers and providers were less successful, even after three years. "They knew they could request information," we were told, but few requests have been received from mainstream organizations.

Several respondents in our partner surveys reported that some CMS materials continue to be difficult for many seniors to understand. Reading levels above what many seniors can understand and lack of culturally appropriate language are confusing to many beneficiaries. As a national partner representing Native American seniors reported:

"[CMS's printed materials about Medicare] are not in plain English. For example, in a diabetes booklet it said, 'Monitor your glucose' when it should have said, 'Watch your sugar.'"

The respondent noted that CDC's National Diabetes Education Program has "*some good Indian materials*" already developed that might be useful to the NMEP/REACH campaign. He also described a six-site demonstration project involving CMS, the Social Security Administration and the Indian Health Service to identify appropriate materials for informing the Indian elder population about their entitlements and choices.

"The materials which are to be developed will be shared through persons which the elders know and trust, so that a much better program of outreach will occur. Up until now we have had to rely on printed materials from [CMS], which presumes that the elder is able to read sophisticated language. We are very excited about this new approach which is from the bottom up, not top down. This approach is not print or media oriented."

Respondents at some sites have created their own translations and materials when needed Medicare information is not available on specific topics of interest or in culturally or linguistically appropriate formats. Awareness and understanding of special populations' needs and resources by intermediaries help to facilitate information flow. In Eugene, OR we observed informal collaboration among community providers that serve special populations to develop special materials for low-income beneficiaries. One respondent at a local hospital seen as a principal provider of Medicare information reported plans to collaborate with the area's only other hospital:

"I will be partnering with [Name] Hospital and AAA to produce a brochure/guide for low income beneficiaries. This happened as a result of a meeting we had with AAA and we thought to bring in the other hospital so we all don't produce different brochures on the same topic."

Another respondent, from the Eugene area, told us:

"More information is available due to a combination of things: 1) I do more outreach, 2) I received [CMS] Medicare+Choice training two years ago so I'm more aware of the offerings—I know what documents are available to people. QMB, our Nursing Home Guide, the general Medicare brochure are especially helpful for adult children of beneficiaries."

For many special population groups, especially Communication Difficulty Segments with limited English language capability, health literacy issues such as basic health promotion, maintenance, and treatment issues affecting beneficiary sub-groups must be addressed before they can understand or be interested in Medicare healthcare coverage information. A national partner interviewed for our Alliance Network feedback study explained:

"[CMS] needs to look into the health needs of U.S.'s minority populations. People are literally dying because providers and others do not understand their language and cannot address their needs...[CMS] could put out basic health information on topics affecting these populations—diabetes, glaucoma, etc. People are hungry for basic information, and [CMS] could make basic inroads in these communities by addressing these topics."

One respondent, funded by CMS to conduct research and develop culturally appropriate materials for Medicare outreach to API populations as part of the *Medicare Beneficiary Grassroots Rights and Protections Outreach Project for Vulnerable Populations* project, spoke of

the need to develop a basic level of awareness of health issues and Medicare within these communities — a necessary first step before individual outreach can really occur, because people in the communities and their own community organizations typically do not understand enough about the context with government systems and healthcare to comprehend even the basics about the Medicare program and health insurance coverage:

“In communities not literate and of color, opportunities are limited to get information. Even though more talk about targeting material, it’s not close enough support for what are health topics in these communities. Health literacy in general is a problem for older people...plus...language, cultural issues, etc. for these communities...Available Medicare information is thin. Change is even more confusing...It is ten times harder for non-English speakers to understand Medicare information... According to the census, these populations are doubling in size...

[Providing effective Medicare outreach to these communities] takes several years, maybe three really targeted ones. A sequential effort starting with Year 1: “What is Medicare A and B? Here’s where you look on your card to find it. It’s hard work, even in large urban areas with concentrated populations of limited English speakers, like New York. But it can be done. You have to work through the community-based organizations that serve these communities.”

We observed several instances where translations were problematic in our interviews with state and regional partners, and REACH activity monitoring. Some RO staff contacted for our partner survey reported that CMS materials for the flu campaign translated from English to Spanish as *“The flu shot will kill you. Therefore, take the flu shot.”* At our Springfield site, a respondent at the Spanish American Union (SAU) commented that a lot of information that the government sends out to Latinos is difficult to understand. Billing issues and related questions about what Medicare does and does not pay for are common sources of confusion for their constituents. Our respondent reported that printed materials are unclear for many beneficiaries. While they do appear in translated form, *“in Spanish words might mean different things to different people.”* We were further cautioned that *“the government should keep in mind many of these people do not read,”* underscoring the importance of making printed information available written in language and at levels people can understand, as well as in formats for those who do not read, such as radio broadcast.

The Eugene AAA, which maintains relationships with various providers (hospitals, physician groups, clinics, medical assistants, social service organizations and care facilities, senior centers, churches, and mobile home parks), also created a local guide to Nursing Home Compare, to hand out because CMS’s information has been *“a bit unreliable”* and was out of print for awhile. Now AAA staff order CMS publications on-line and praise this service — an improvement over the fax requests, used previously, which involved long delays. This respondent created an order form for materials, including QMB guidance, and told hospitals how to order it themselves, increasing local demand for CMS materials. She suggested that on-line access would be helpful for hospitals, and particularly for social workers.

In Springfield, the Council on Aging (COA), the host agency of the SHINE, has taken steps to provide information and translations at the community level. The SHINE recently included a Spanish language section in its general newsletter, and plans to include sections in Russian and Vietnamese. The COA also reported plans to direct mailings to African American beneficiaries who do not generally attend their local meetings and presentations.

5.3.2 QMB/SLMB Issues and Poor Beneficiaries

Lack of suitable information about Medicaid buy-in assistance through QMB/SLMB was widely reported in our six monitoring sites. Local efforts to produce materials is common. Confusion also exists among the non-Medicaid eligible poor beneficiaries about prescription drug coverage which might be added to Medicare.

State SHIPs described their considerable efforts to increase enrollment in QMB/SLMB. For example the New York SHIP is part of a task force to increase outreach to beneficiaries eligible for QMB/SLMB, signing up 300 beneficiaries for QMB/SLMB during a one-day event for seniors. Rhode Island did a direct mailing to 8,000 low-income seniors regarding Medicaid buy-in programs, and plans to print information about Q-I-1 on EOMBs.

A SHIP partner in Region 5 reported working with Medicaid agency staff to help improve understanding of QMB and the rest of Medicare. The SHIP also reported needing to give information to hospitals so patients know their rights. This partner suggested that SSA offices should incorporate a Medicare specialist/representative to answer beneficiaries' questions. According to the partner, this would decrease call volume for other partners.

Several SHIPs described collaborations with intermediaries or partners to reach special population groups. A West Virginia SHIP discussed plans to focus on inner city housing projects and related recruiting of SHIP volunteers from among the targeted outreach group and advocates. South Carolina described their use of students from historically black colleges to do SHIP and QMB/SLMB outreach.

In Region 6, a SHIP partner reported having undertaken efforts to link SSA, Medicaid, and Medicare to increase eligibility:

“One of the biggest problems with dual eligible programs is that Medicaid and SSA don’t work together...The data systems are set up to identify in-eligibles. We should move forward and have SSA identify eligibles. Beneficiaries are experiencing problems. CMS could help get discussions with SSA and IRS, Medicaid going in a larger sense, get them to the table to talk. We feel our hands are tied and we don’t have the time and resources to push it forward...CMS could be an advocate to help with these agencies.”

One AAA director we interviewed for our site monitoring expressed particular concern about beneficiaries' confusion about coverage and access to affordable options, and their rising expectations following media attention to the prescription drug issues in the recent presidential election. This respondent observed:

“There’s a huge expectation among seniors that the problem [prescription drug coverage] is a few months away from being solved, since the election. I believe it’s more likely to be at least a year or so, and through more restrictive policies...We need to be careful to

maintain expectations. Many think the solution is right around the corner, they're expecting it."

State partners expressed concern for beneficiaries with fixed or low incomes who are unable to afford supplements or who do not have access to prescription coverage through managed care plans. For example:

"Beneficiaries are concerned about information about drug coverage on the news. They decide not to eat to pay drug bills. There is a state drug program, but many don't use it. Many beneficiaries have lots of pride and don't like to think it's welfare. We tell them it's not and encourage them to use the program, but they don't."

"[We have] two types of seniors: seniors who live in poverty and seniors who do not. Seniors who fall below the poverty threshold are eligible for Medicaid and other social welfare programs that help them finance their prescription drugs. Seniors who fall just above the poverty level are not eligible for these programs and fall through the cracks. These seniors have to make a choice between buying their medications and buying food. They often end up neglecting their medications. Seniors in rural areas often neglect themselves so that when they finally do get to a hospital their condition is often twice as bad."

This respondent noted that Medicaid QMB assistance is underutilized because beneficiaries don't know about it. She explained that she learned about it through AARP volunteers. Our respondent added that, although the state has a QMB chart, CMS's brochure and income comparison chart are *"far superior to the state one. CMS's is clear and precise, and helps people right away to understand QMB."* The AAA uses CMS's guide and has been pleased with its applicability and use by local beneficiaries.

One SHIP partner interviewed for our Regional Partner Feedback Assessment described new efforts for Public Benefits Outreach and screening to assist low-income beneficiaries in stretching limited healthcare dollars. According to this partner, the SHIP uses a screening tool to try to connect low income beneficiaries with housing, energy assistance and other programs, and to help them qualify for dual eligibility with Medicaid. He also described pilot projects that place SHIP volunteers at Medicaid offices to assist beneficiaries with program eligibility and enrollment.

5.3.3 Language Barriers to Accessing Plan-Specific Information

In our site observation work, we have heard that sometimes plan choice is restricted for beneficiaries who do not speak English. These situations seem to be due to both cultural and language barriers. Populations such as the disabled also face limited choices due to providers' perceptions of costs of serving these groups. While these kinds of problems do not arise because of information deficits, they may be resolved by improving Medicare information accessibility.

Plans certainly have limited provider and service capability to adequately serve many special populations, especially when cultural and language barriers exist. Perceptions are also widespread among community information suppliers that the needs of many of these special groups (disabled, low income, very old or chronically ill, etc.) may be better met through their current providers in the fee-for-service sector than in health plans. Plans are also often

reluctant to serve disabled beneficiaries due to assumptions of the cost of serving these populations. Individuals with fixed or low incomes across all demographic categories faced barriers to choice related to cost across all sites, especially those who do not qualify for Medicaid and QMB/SLMB.

For many non-English speaking sub-groups Medicare information is limited—but information on plan choice is largely non-existent. We heard reports that, in API communities, little Medicare information is available, and very little if any exists at the state level. Restricted plan choice may, in fact, have benefited some limited English-speaking sub-groups in communities facing withdrawals. One respondent reported:

“I don’t think many limited English speakers were enrolling in plans, most weren’t affected by the pullouts because they were in fee-for-service Medicare. But I don’t really know. This is probably good, that not many are enrolled, because if they join they find the providers don’t speak their language and they don’t understand the services—they are poorly served. We encourage people to stay with the providers they know, who serve them in their languages, usually in fee-for-service...”

...Some plans are now getting it that limited English elders are good to target because their utilization of services is low. They hire a bilingual marketing person to go into the community and sell the plan. The elders are fooled, thinking providers in the plan will also speak their language, know the community. What they find is that providers speak only English and can’t serve them well. It is probably a good thing NOT to market Medicare choices to these communities, because there are no real choices for them.”

5.3.4 Special Population Plan Choice Issues in Tucson

In Tucson, where managed care options have been numerous, choice appears to be limited for disabled beneficiaries seeking Medigap coverage. The two available supplemental policies are available to disabled and other beneficiaries, but are not actively marketed, we were told. Health insurance agents reported they would receive no commission on sales for guaranteed issue policies to the under-65 disabled population (contrasted with 25 percent of premium for the >65 population); commission rates for the disabled were later changed to only five percent of premium (under pressure from the Department of Insurance). As a result, many are unaware of their supplemental options and sales of supplemental policies to this sub-group are limited. The local SHIP here also reported making presentations to organizations serving people with special health conditions (ostomy, Parkinson’s, transplant survivors, etc.), tailoring presentations to the insurance choice options pertinent to each.

Health Net (formerly Intergroup Health Plan) in Tucson has made significant efforts to market to the area’s large Hispanic/Latino population, but has met limited success. The managed care plan has three Spanish speaking representatives who handle Spanish speaking enrollees, educating them on plan products and services, and reported spending *“a lot of money trying to market to them and it didn’t happen.”* While local Hispanics do enroll in the plan, they do so by home appointment and word of mouth, assisted by family members.

“They don’t go to seminars, they don’t go to meetings...word of mouth works best for us.”

The plan reports that it is through family members that they have reached this community.

“They are a very cautious group of people...[When they come to the office] they come in as a family and very often with their son or daughter who speak English a little better. They are even scared to talk in Spanish to our Spanish speaking reps about insurance policies. This is distrust!”

Local Hispanics do enroll in the plan, however. Intergroup is also involved with disabled groups and with centers for the blind and hearing impaired, and helps them sponsor some of their events in the community, such as the Special Olympics.

5.4 Information Supplier Partnering

Increased involvement of partners in providing Medicare information was a consistent theme in our site monitoring, state partner interviews, and REACH assessments. We observed collaboration involving formal information intermediaries (such as SHIPs, community-based organizations, providers and employers) and informal information intermediaries such as adult children and grandchildren. Partnerships are seen as especially important for reaching passive and reactive information seekers, in all four special populations segments. All ten Regional Offices identified partnerships and collaboration with intermediaries and partners as critical links in planned efforts to reach special population sub-groups, and included partnership development and outreach as a focus of their REACH 2000 Business Plans (see section 2.1 earlier for other analysis of REACH business plans).

Our monitoring of six study sites, NMEP/ REACH partners and REACH activity assessments have all indicated that Communication Difficulty Segments and Situational Segments involve more use of partners. Situational Segments received priority attention through partnered non-renewal events in many communities affected by plan withdrawals. These events usually targeted mainstream beneficiaries, with few activities directed specifically to beneficiaries with more complex information needs. Local collaboration to reach Communication Difficulty Segments, including limited English-speaking sub-groups, generally focused on general Medicare program information, although efforts to reach these sub-groups appear limited in number and scope.

We observed minimal partnering or collaboration directed to Vulnerable Segments or Special Opportunity Segments in our six monitored sites last year, although partnered activities for these groups was reported outside of our sites, by state and national partners in the ten CMS regions. However, state partners described events and activities including van tours for low income and rural sub-groups; presentations at high schools and universities to reach adult children, grandchildren and other caregivers; and collaboration with programs such as Meals on Wheels to reach passive, homebound information seekers. Media partnerships and collaboration were reported in all regions, targeted to both general beneficiaries and cultural/ethnic sub-groups. Summary information on use of intermediaries, partnering and collaboration for special populations and general beneficiaries is provided in Table 5.3 below.

Table 5.3
Partnering and Collaboration for Special Populations

Source	Communication Difficulty Segments	Situational Segments	Vulnerable Segments	Special Opportunity Segments	General Medicare Population
Site Monitoring In Six Cities	-training, outreach to ethnic, other community organizations -hiring bilingual staff -web-based translated information	-extensive REACH partner collaboration re: withdrawal events	-activities for the homebound and frail		-REACH partner collaboration for events, -partnering with senior organizations re: general Medicare and withdrawals -information networking
State/Regional Partnering Study	-SHIP partnering with ethnic, other community organizations -outreach to ethnic broadcast and print media	-targeted partnered presentations	-public benefits (SHIP) outreach -linkages with Medicaid, SSA -collaboration with hospitals, providers -homebound outreach through Meals on Wheels	-partnering with employers, faith-based organizations, high schools and universities -new enrollee mailouts prior to 65 th birthday	-REACH partner collaboration for events -partnering with senior organizations re: general Medicare and withdrawals -information networking -toolkit for social workers
REACH Assessment	-radio call-in shows -partnering with non-traditional partners (housing, ethnic community organizations) -CBO activities for API outreach	-targeted partnered presentations	-rural van tours	-employer trainings -library project	-REACH partner collaboration for events, -partnering with senior orgs re: general Medicare and withdrawals -information sharing and networking

Source: Abt Associates NMEP/REACH Monitoring, 2000.

In the examination of these activities we reach several conclusions about the partnering activities. Information providers who are attempting to serve special populations emphasized the importance of making connection with and working through community-based organizations that serve these populations, and encouraging these organizations to provide outreach and information through established and trusted networks in these communities. Partnering activities we studied as part of REACH 2000 suggest that the ROs are becoming more aware of the value of using local coalitions of not-for-profit organizations to better reach some special populations, particularly the Hispanic/Latino and API populations. In South Florida, the RO has been featured as a guest on Hispanic radio talk shows addressing callers' Medicare questions. Activities in Seattle by the NAPCA in conjunction with the RO, and the related translated materials there have been spreading to places like Houston and Philadelphia, and nationwide through the Internet. The Seattle RO recruited a large coalition of API community organizations to work with it in planning and implementing a health fair targeted at API seniors. Coalition building offers a partnering strategy consistent with social marketing in that it provides an opportunity for CMS to not only educate partners about Medicare, but it provides an opportunity for CMS to listen and learn from coalition members about the special needs and behavioral barriers of the special population.

We observed more active partnering and collaboration with community organizations to reach special populations as part of our REACH 2000 monitoring. New and more active partner relationships identified in the ten regions include: Region 1's involvement with a Multi-cultural Coalition; Region 3's partner activities with the NIH Center on Black Aging, the VA, and Asian Outreach Committee Employers; Region 8's involvement with a Patient Advocacy Coalition (a SSA partner); and similarly broad-reaching partnerships reported in other regions. Two regions (Regions 4 and 6) reported new or active partner relationships with AARP. Three Regions (Regions 2, 5, and 7) are now partnering with Osco Drugs, and a fourth (Region 10) is partnering with Albertsons Drugs. Region 7 has made particular efforts to develop

relationships with private sector organizations, including CIGNA and DMERC. New or more active partnerships were also reported with various media in Regions 2, 5, 7, and 10.²⁵ Region 3 conducted a mass mailing to minority media. Region 9 staff also include media in reaching sub-populations: “*media has a multiplier effect on events,*” increasing turnout.

Situational Segments, including beneficiaries affected by managed care withdrawals, received priority attention by NMEP/REACH partnerships in many communities in 2000. SHIPS, RO staff, carriers, fiscal intermediaries, PROs and other partners formed the core of these events. At our Olympia site, where plan withdrawals and a ceiling on enrollment in one plan last year have left Group Health Cooperative as the sole managed care plan accepting new Medicare enrollees, the local SHIBA conducted close to 20 workshop presentations. Most withdrawal events were given as presentations with a focus on general beneficiaries, and most affected communities reported providing substantial information and counseling by phone and in-person to help address local plan changes. Our monitoring interviews and analyses suggest that beneficiaries who fall into more than one of our four special population categories may have experienced the most urgent needs for information. In our REACH monitoring of non-renewal events we found that language is still a barrier for many; it is helpful to have plan termination letters, non-renewal fact sheets, local comparison charts, rate guides and other materials available in prevalent languages.²⁶

During our REACH 2000 monitoring we observed several types of partnering activities that targeted special populations including persons with disabilities, employer groups, and special cultural and ethnic audiences. Sample activities are described in Table 5.4, below. These data show that ROs are certainly becoming more aware of the value of using local coalitions of not-for-profit organizations to better reach some special populations, particularly the Hispanic and Asian Pacific Islander(API) populations. One example was the talk show appearances by an Atlanta RO staff member on several Spanish language radio stations in south Florida. To reach the Spanish-speaking population in South Florida, the RO organized a media blitz of radio stations, with the aim of developing regular appearances on various shows with senior audiences. As part of this effort, a bilingual RO staff member has been a guest on local Spanish language radio call-in programs addressing Medicare beneficiaries' questions and issues.

As for live events, the Asian-Pacific Islander Health Fair in Seattle was quite innovative in reaching its target groups. In the Seattle area, a coalition of local partners organized under CMS RO leadership sponsored a large health fair in a suburban church. The fair included booths, health screenings, and interactive information games aimed at conveying Medicare information across language barriers to seniors from many different Asian/Pacific Islander communities. The event brought together mainstream information providers and ethnic community-based organizations who provided "language escorts" for the beneficiaries. Several new partners, some solicited by the RO and others who called the RO directly, were developed as a result.

²⁵ Abt Associates Inc., op. cit.

²⁶ Abt Associates, Inc., “The National Assessment of the 2000 REACH,” CMS Briefing: Preliminary Findings and Recommendations, January 24, 2001.

The partnering efforts that center on special populations are part of a larger evolution of NMEP/REACH partnerships. Several ROs reported taking a more active role in developing and maintaining partnerships in 2000, and most expressed satisfaction that their partnership relationships have continued to improve. For many, their increasing role working with partners seems to drive the level of satisfaction ROs feel. One RO described changes to their role regarding NMEP/REACH partnerships as the Regional Office and the partners have become more experienced and the partnerships more mature. Our respondent reported:

“Our role has changed. At first we were just trying to get partners—recruitment. Next, we focused more on Medicare. Now, with technology and a good base, we’ll need to focus on staying in touch through quarterly newsletters, etc.—maintenance”—Regional Office

This respondent also commented on the need to recognize differences in types of partners as well as the approaches to their participation and involvement. The RO noted that three types of partners have participated in the regional partner activities to date:

“...Some partners will not be a partner every year. Some are a) one shot, b) once every 3 years for special events, c) ongoing—our SHIP counselors, for example. We need to focus on maintenance for on-going partners, and keep recruiting others on an on-going basis...Partners are now less dependent on us, more collaborative. It’s less of an ‘Indian Chief’ approach.”

Table 5.4
Partnering Activities in Abt Associates' REACH 2000 Activity Monitoring Sample

Event	Type of Event	Place (3)	Sponsor(s)	Targets	Special Population Focus
Disability Advocate Training	Didactic with QA	3 sites in NJ	State Office on Disability with support from Intermediary HH Industry, DMERC RO.	Independent Living Center staff; NJ Offices for Disabled (48 across 3 sites). Some attendees were not outreach workers.	Yes; about ¼ of trainees were disabled.
Asian Coalition Building	Didactic with QA	Houston	RO with help from NAPCAR Regional Rep. SSA invited to speak.	Community Agency staff (13 of 15 were Asian).	Yes
Train-the-trainer Workshop (first time event)	Didactic with QA	Boise	SHIP supported by RO, Carrier, PRO	Community case workers, counselors, senior organizations (30).	RO discussed reaching Special Populations.
Tri-region Employer Conference	Didactic with QA plus booths	Philadelphia regions I, II, III	Northeast Consortium and RO 3 supported by each RO, SHIPs, SSA, DOL, and NY COB contractor.	Employer HR staff (42 employers plus partners).	Special Opportunity target of employed persons about to retire
Tri-annual HICAP Conference	Didactic and panels. Not primarily Medicare related.	Sacramento	HICAP with support of Dept. of Aging, RO, and contractors.	SHIP program managers (24 in the N. California area), plus HICAP, CMS, and CDA staff (55 total).	RO discussed unreliability of translated materials. One presenter on assistive technologies.
Secondary Partner Training (third Year multi-Site training Event)	Didactic with QA plus follow-up newsletter.	El Paso (one of many sites)	RO supported by TX Dept of Insurance and local SHIP.	Secondary partners (providers, community agencies, exiting plan, military); (35 partners plus some others).	No, though both presenters bilingual.
Tele-Broadcast to Partners re: Non-renewals	Didactic plus panel; no QA.	35 locations in Pennsylvania (Sunbury, PA was observed).	RO supported by Depts. Of Aging and Insurance plus VA and Med. Society.	400-500 partners (7 in this one location), provider staff, congressional staff, SSA, community agency staff.	ESRD social workers
Training Community Social Service Workers (Secondary Partner Training)	Didactic; choice of 2 tracks.	20 locations (Saco, ME was observed).	Beneficiary Services Workgroup members and the Ambulatory Care Coalition	Staff and volunteers from many kinds of organizations (about 430 trained).	Effort to develop "tracks" for Native Americans, veterans, rail retirees.
PA Library Project	Planning activity to distribute tailored library version handbook to 720 libraries in Pennsylvania – not yet completed.	Pennsylvania	RO with the Library Services for Older Adults Task Force	All public libraries in PA (720).	In general, no. Some copies in Braille were distributed.
Asian Coalition Building	Collaborative activity for planning outreach to Asian seniors in Philadelphia	Philadelphia	RO with Minority Coordinator of Philadelphia Corporation on Aging	Asian beneficiaries in area, especially non-English speaking seniors	Yes, RO consults with PCA on planning outreach to Asian community
Monthly Partner Newsletter	Updates on important REACH issues and events distributed to RO partners	Region IV	RO staff	Regional partners (some technical barriers currently hinder distribution to all partners)	Outreach to special populations described in newsletter stories

Source: "The National Assessment of the 2000 REACH," CMS Briefing: Preliminary Findings and Recommendations, January 24, 2001.

Both ROs and partners emphasized the importance of accountability by participants to the goals and objectives of the partnership, with defined roles and expectations. Some called for more formal arrangements that reflect these roles.

“Partnership development is putting together mutually beneficial relationships that are on-going and measurable.”

Both ROs and state partners asked for more program accountability — including Medicare program data and community demographics as well as information on the effectiveness of various outreach approaches — as the partnerships expand to reach special populations and beneficiary groups who have been difficult to reach through general outreach approaches. There is widespread recognition that resources must be carefully targeted and applied to effectively reach special population segments and make appropriate use of scarce program dollars.

CMS should continue its support of this trend by offering partner trainings in successful methods to identify the needs and means of reaching these segments of the Medicare community. The activities in Texas sponsored by the RO to train secondary partners are a good example of how a large program of this activity might be structured. While there is general recognition that non-traditional partners can enhance the potential of REACH partnering, their inclusion as partners challenges CMS to develop guidelines and administrative mechanisms to facilitate their participation. This is especially true with partners from private industry. ROs and partners in several regions have established or engage in collaboration with partners other than CMS's core information suppliers, government agencies and community-based not-for-profit organizations. Issues concerning how to establish public-private partnerships with CMS, including concern about potential conflict of interest and parameters for use of government and private resources, have been difficult and challenging to address. However, interest and support for developing these relationships, and finding ways to encourage non-traditional partners' participation as REACH partners is considerable and growing across all CMS regions.

With respect to the activities in the six sites we have been monitoring, we observed limited but growing interest and involvement with partnering to reach special populations, in particular in our Olympia, WA; Springfield, MA; and Eugene, OR sites. In Olympia, new collaboration involving Group Health Cooperative of Puget Sound and the state SHIBA was reported in 1999 to provide presentations on the plan's withdrawals to beneficiaries in several rural service areas in Eastern Washington. Group Health reported positive benefits resulting from this new relationship statewide that continued through 2000 to the present. Local congressional staff also reported new collaboration with SHIBA to conduct Medicare presentations and workshops in the Olympia area last year. At our Springfield site, the Spanish American Union reported feeling “*more in the loop*” with mainstream providers in 2000 than in previous years. While SAU still is not fully integrated with mainstream information suppliers, our respondent now attends monthly SHIP trainings sponsored by SHINE and its host agency, the Council on Aging. Partnering and collaboration also appear to be developing informally in Eugene, as healthcare providers begin to identify unmet needs and work together to develop targeted information and materials for low-income beneficiaries.

We observed little evidence of partnering and collaboration in Dayton, Sarasota, and Tucson. However, Sarasota did host a non-renewal event for Spanish-speaking beneficiaries that included the Medicare PRO as a partner. In Tucson, the Arizona Beneficiary Coalition, a strong, statewide partnership, focused considerable effort on outreach in orphaned rural counties outside Tucson, but little effort in the city proper.

State and national partners provided some examples of successful activities conducted for special populations. For example:

- **Tribal Communities.** A SHIP partner in New Mexico described a special pilot project conducted with AARP three years ago to provide public benefits outreach and enrollment to Navaho and other tribal communities, reporting: *“We worked with the tribal committee to get permission to work with the community through a ‘proclamation’ that allowed door-to-door outreach. They gave their blessing, permission and support to use their traditional ways. We trained Navaho staff. AARP provided resources, including gifts of food. Then we did a screening of folks for eligibility...using the basic SHIP intake form which addresses benefits like food, home repair, health...We try to connect them with a local counselor...You have to do a lot of follow up, many person hours. Very worthwhile...very time consuming.”* This highly successful program is currently being extended to other tribal groups and communities in the region.
- **Hispanic/Latino TV and Radio Talk Shows.** To reach the Spanish-speaking population in South Florida, the Atlanta Regional Office organized a media blitz of TV and radio stations, with the aim of developing regular (monthly) appearances on various shows with senior audiences. A Public Affairs specialist developed a means to get news releases directly to small radio stations throughout the region, enabling the RO to get their news stories distributed quickly. As part of this effort, a bilingual RO staff member has been a guest on local Spanish language radio call-in programs addressing Medicare beneficiaries’ questions and issues.
- **Asian-Pacific Islander Health Fair.** In the Seattle area, a coalition of local partners organized under CMS RO leadership sponsored a Health Fair, a large event held in a suburban church, that incorporated booths, health screenings, and interactive information games aimed at conveying Medicare information across language barriers to seniors from many different API communities. The event brought together mainstream information providers and ethnic community-based organizations. Several new partners, some solicited by the RO and others who called the RO directly, were developed as a result.
- **Employer Retirees.** CMS’s Alliance Network partners at Towers Perrin, General Motors (GM), and the American Federation of State, County, and Municipal Employees (AFSCME) include Medicare information in their health benefits materials and presentations for retirees.²⁷ Since 1994, Towers Perrin has sponsored the Retirees Choice Coalition, a group principally consisting of Fortune 500 employers who sponsor post-retirement health plans, representing 2.5 million employees. The coalition partners

²⁷ Based on presentations to the CMS Advisory Panel on Medicare Education (APME), April 26, 2001.

with CMS at the national and local levels, and provides CMS materials, corporate presentations, phone service and uses SHIPs to assist retiree decision making. It has been successful in securing competitive premiums for enrollees who choose Medicare+Choice options. GM's employee education program also partners with CMS at the national and local level to educate retirees and pre-retirees using materials from CMS and other sources, and partnerships with SHIPs, PROs, and coalitions. GM also participated with CMS in the Kansas City "Medicare Awareness Day." AFSCME's retiree program provides its retirees with Medicare materials produced with another Alliance Network partner, the Medicare Rights Center, and materials on Social Security and Medicare from Alliance Network partner William M. Mercer, Inc. It also provides AFSCME materials, seminars and counseling on Medicare.

6.0 Summary of Findings

6.1 Overview

This paper synthesizes the results of Abt Associates' National Medicare Education Program (NMEP) and REACH monitoring and evaluation activities as they pertain to special populations. The primary issue is which sub-populations among the beneficiaries need special attention by the NMEP in order to achieve the objective of “informed choice”, and what do we know about the approaches that may be most promising for meeting these needs.

The principle findings in the sites we are monitoring for CMS are:

- that some identifiable sub-populations (or segments) of Medicare beneficiaries are different in the way they use information and the way they respond to the NMEP activities,
- there do appear to be unmet information needs among some sub-populations of beneficiaries and
- though it is still early in the experience of the NMEP, and in spite of REACH efforts to give priority to special population needs, little attention is being directed by local information suppliers at special population information needs.

Attending to the information needs of sub-populations is very much a local matter — where unmet needs can be identified, solutions fashioned and implemented, and where local partners can be engaged to help. Some evidence does exist of systematic (i.e., national) unmet needs for information for identifiable sub-populations, particularly for persons with urgent situational needs for information. But for chronically vulnerable sub-populations (like minorities, the poor, and those living alone) the evidence of unmet needs and restricted access to information sources is less systematic and may be subject to wide local variations — in such cases, national partnering and collateral development activities are of limited help. We find, however, that local information suppliers are, for the most part, not yet engaged to meet such special population needs, nor equipped to do so in most cases. It is encouraging to note that REACH monitoring has identified interest in several locations of concerted coalition building activities as an intensive way for making connections and providing information to sub-populations with special needs.

There is still a lack of consistency in thinking about special populations across the NMEP program: who they are, what it means to be ‘special’, and what to do differently in trying to achieve consistently high levels of informed choice across Medicare sub-populations. This lack of consistency is evident in the literature, in REACH planning and strategy materials, and in the work of information suppliers in the six sites we have been monitoring. To be sure, the strategy of REACH was to allow regions the flexibility to identify the special population needs and solutions, rather than imposing a programmatic view. Most sites do not have a clear picture of their special populations, or their information needs. Some sites report targeting populations identified by their Regional Office; however, many sites reported that RO-defined special populations did not reflect local beneficiary demographics or characteristics. Sites named other populations, ranging from military retirees, limited and non-English speaking

immigrants, older and frail beneficiaries, and rural residents to more traditional demographic groups based on race or ethnicity.

There appears to be broad categories of the Medicare sub-populations, each with particular special needs. We suggest that there are four ‘special’ kinds of segments within beneficiary populations in every locality. Several things can be special about segments of the population. Basically, they would be special if they were known to seek information or learn in ways that were not able to be as effective as for the mainstream beneficiary. Or, they would be special if their needs for information are unique. If population segments are ‘special’, they may warrant some unique channels of information, or some unique messaging, or both. These four types of segments, while all special, may help to clarify the situation for REACH and other planning activities:

- **Communication Difficulty Segments** — these persons have difficulties communicating using channels and messages designed for the majority of beneficiaries because they are culturally isolated and hard to reach, or because they have language barriers. Includes Rural, non English speakers, institutionalized, and others with cognitive impairments.
- **Situational Segments** — those beneficiaries who experience an urgent situational need for information about Medicare — because their plan dropped them, their doctor left their plan, they have a financial emergency, their health has worsened, their spouse died, or their employer changed the retiree benefits.
- **Socially Vulnerable Segments** — those beneficiaries who belong to a population group which may be chronically vulnerable to the choices and complexities of Medicare itself — or because they have limited means and restricted choices. These groups include the very old and frail, the poorly educated, the poor, those in poor health, persons who live alone, or are disabled.

These three segments relate to special beneficiary needs. The last segment, below, is related to CMS needs and special information supply opportunities, and does not clarify whether there are ‘special’ needs of these beneficiaries:

- **Special Opportunity Segments** — those beneficiary groups that may represent special opportunities for CMS to reach portions of the Medicare population in special ways or with high leverage (e.g., new enrollees, persons covered with insurance by large employers).

We describe our findings for each of these groups. These sections in the Summary are followed by sections that report findings about how information suppliers are dealing with special populations in the sites we are monitoring, and how partnering is being done.

6.2 Findings Pertaining to Particular Segments of the Population

Findings Pertaining to Communities in Difficulty Segments

Little is known empirically about these kinds of sub-populations from the literature or from survey data. While rural persons are lower users of covered services, there is nothing explicit in the literature to suggest that they suffer information deficits, nor is there evidence that they or linguistic challenged sub-groups are making poor choices or suffering in other ways from information deficits. The presumption is that persons not able to read and understand English, or persons impaired cognitively have unmet needs for information about Medicare. We have heard that sometimes plan choice is restricted for beneficiaries who do not speak English. These situations seem to be due to both cultural and language barriers. Populations such as the disabled also face limited choices due to providers' perceptions of costs of serving these groups. Plans have limited provider and service capability to adequately serve many special populations, especially when cultural and language barriers exist. Perceptions are widespread that the needs of many of these groups may be better met through their current providers in the fee-for-service sector.

New attention is being focused to methods and approaches of dissemination that target formal and informal local community based intermediaries (i.e. persons or organizations who are in the middle) who can assist non-English speaking beneficiaries. Translated materials are more widely available through CMS and other sources, and are disseminated when their availability is known. However, availability of these materials is not widely known by information suppliers and intermediaries. New technologies such as web sites are important tools — increasingly popular with information intermediaries, including formal organizations (traditional partners as well as community-based organizations serving special population groups) and informal interpersonal supports (adult children and grandchildren, friends and other family members). Materials have been developed by CMS and other organizations at the national, state and local levels. Efforts are needed to help promote access to these materials.

While translated materials are becoming more available in local sites and at events, simply translating materials into other languages is likely to be inadequate to address the problems of linguistic minorities. Increased availability of translated materials is due, in part, to CMS-funded efforts. However, these linguistic minorities often require materials and approaches that address basic health literacy and content beyond mere translation of information about Medicare in more or less the same fashion that it is made available to mainstream populations. And, proper translation of technical terms about Medicare is often difficult; native terms for many health insurance concepts do not often exist; word by word translations do not often convey the intended meaning due to cultural context differences.

Channels for distribution of information to these populations (and other sub-groups) are relatively undeveloped at most sites we monitored. Most community organizations and local information suppliers in the sites we monitored do not have staff or resources to adequately address the needs of such groups, especially when language barriers exist. Some information providers report having one or more part or full time staff with some bilingual capability, but most receive few requests for information and fewer still reach out to local leaders and organizations in these communities. CMS's support is important in meeting suppliers' needs for providing information and building broad awareness in the form of materials, training, and media.

Findings Pertaining to Vulnerable Segments

Minorities and other socio-economically vulnerable groups are clearly less satisfied and less knowledgeable about Medicare than other groups, and experience choice difficulties and access problems for services. There are consistent suggestions from the literature that the very oldest beneficiaries, the poor, the poorly educated, those in poor health, and persons without supplemental insurance experience problems coping with Medicare (access, satisfaction, choice difficulties). The findings on minorities and those living alone are less consistent.

Information usage by these groups is not uniform, with disabled beneficiaries tending to use information about Medicare more often, while the poorly educated, and the older beneficiaries, tending to use information less often than other beneficiaries. There is also evidence that the “other minority group (including Asians, and some native Americans) tend to use information more often than other beneficiaries, and some indication that live alone beneficiaries use information sources other than the handbook less frequently. Use by other vulnerable groups (African/Hispanic Americans, those in poor health,) does not appear to be lower than other beneficiary groups.

Individuals with fixed or low incomes across all demographic categories faced barriers to choice related to cost across all sites, especially those who do not qualify for Medicaid and QMB/SLMB. In one site we were told that Medigap plans are not being actively marketed to disabled beneficiaries—agents did make it available, but receive a 0 percent commission, discouraging sales.

Disabled beneficiaries are consistently less satisfied with their access to Medicare information than other beneficiaries, tend to know more about Medicare than others, and use information about Medicare more frequently.

We conclude that the disabled persons are a clearly defined segment with a special situation, with different seeking behaviors for information. They are also more likely than other Vulnerable groups to experience urgent situations that prompt a search for information.

Findings Pertaining to Situational Segments

Situational Segments of the population are important ‘special’ group of beneficiaries. They experience acute needs for particular types of information in order to cope. Focus groups and the research literature demonstrate repeatedly that beneficiaries can and do often react to specific, immediate situations by searching for information. These take the form of events in their lives and events related to insurance markets. According to our survey findings and site reports, beneficiaries have a greater likelihood of searching for information associated with occurrences of:

- physician withdrawal from a managed care plan,
- managed care plan withdrawal from Medicare, and
- change in employee retirement benefits.

One or more of these events occurred in CY 2000 for about 25 percent of beneficiaries in our sites, and this raise the likelihood of a beneficiary seeking information about Medicare about 9

to 14 percentage points, a relatively large effect. Other kinds of events that could create “situations” in the lives of beneficiaries were also generally found to increase information utilization. These “life events” occur for about 36 percent of beneficiaries in a year, and include:

- death of a spouse (no evidence of increase demand for information from this group),
- worsening of health status, and
- personal financial difficulty.

We examined the situation of involuntary disenrollees from health plans in greater depth. In 2001, our NMEP Community Monitoring Survey shows that disenrollees (less than 5 percent of the beneficiary base in our monitoring sites) sought information at rates 17 percentage points higher than the overall beneficiary average. CMS’s EDB data for our monitoring sites show that the burdens of disenrollment fell disproportionately on the Hispanic population due to their higher enrollment in managed care at the sites. This may or may not be a consequence of language difficulty. Hispanics are much more likely than other named groups to have enrolled in managed care (38.5 percent, compared to an average for all beneficiaries of 24.5 percent). This causes the involuntary disenrollments in the monitoring sites to disproportionately burden the Hispanic segment (over 7 percent of the Hispanic beneficiaries experienced involuntary disenrollment, against an average for all beneficiaries of under 5 percent). Blacks and other sub-populations in these sites were not differentially disadvantaged by the disenrollments.

We examined those persons who were involuntarily disenrolled and reported not using any Medicare information during the year (about 17 percent of all disenrollees). Focus groups with these persons (disenrolled but reported no use of information) suggest that some persons may be relying on another family member for guidance, and others actually sought information about insurance, but did not feel it was qualifying for the specific survey questions. Profiling persons who were disenrolled but did not seek information using the survey data, we find that, compared to disenrollees who did seek information, the non seekers tended to live alone, have less education, are more often minority and in poorer health.

Findings Pertaining to Special Opportunity Segment

New Enrollee beneficiaries (aged) are different than other beneficiary groups in their use of Medicare information. New enrollees — those who are exactly 65 years of age — tend to know less about Medicare than other beneficiaries, are more satisfied with the information they have about Medicare and they consistently search for Medicare information at rates much higher than the overall rates of other age groups. For the year 2001, for example, approximately 79 percent of new enrollees sought information, compared to 69 percent for the whole population. New enrollees are more than twice as likely as other beneficiaries to use the Internet and counselors to find Medicare information, and appear more likely to use helplines and the handbook as well.

It is too early to tell consistently if the NMEP and REACH efforts are impacting the special populations groups themselves. We do see improvements at the level of partners and other information suppliers—there is more awareness of these populations; there are more materials and supports available. Yet suppliers still do not have much time and resources to address the issue. CMS’s support is important here in continuing to provide materials and training.

6.3 Findings Pertaining to Information Supply Programming and Suppliers

Special populations and their needs are defined and need to be addressed primarily at the local level. Our monitoring work indicates that local communities vary greatly with regard to awareness, understanding, and resources to meet the special information needs of particular sub-populations of beneficiaries. In some cases these efforts are supported or strengthened by state, regional, and national activities and materials, but local sites are the front lines and the nexus of action to address special population information needs. Developing awareness of and activities for special populations is a process that involves considerable time and effort, often evolving over several years as organizations and coordination mature. Sites seem to do better with one or more lead organizations with: 1) willingness to prioritize special population needs, and 2) commitment of resources to hire and support staff, make available materials and information to support outreach, and to develop and sustain an inclusive culture that supports efforts to reach special populations.

Special populations are not a primary focus of local information suppliers. Most organizations in the sites we monitored do not have a systematic approach or strategy for targeting special populations and the information networks, if any, that may serve them. Most respondents identified special populations activity based on RO suggestions or local anecdote, and provided information on a demand-response or incidental basis. While there is some evidence that *awareness* of the needs of special populations is increasing at the regional, state and local levels, noticeable efforts to address their information needs, to collaborate with community organizations serving special populations or to develop a sustainable Medicare information infrastructure for these sub-groups is limited. Addressing these needs is difficult, time consuming, and interpersonally challenging—and most organizations at the state and local levels are unaware of and ill equipped to address them. Exceptions are sites and organizations with strong leadership, awareness, commitment and will to innovate, commit resources, and establish an organizational culture that supports diversity and special populations information needs.

6.4 Findings Pertaining to Partnering

Because many special populations are present in small numbers, they are difficult and costly to reach. These populations, typically those with communication difficulties and socially vulnerable groups, appear to be most effectively reached through their own community organizations and networks. Partnerships and collaboration with organizations and groups are widely viewed as the most effective means of providing information to special populations, providing the NMEP with greater leverage in addressing their diverse needs. Effective partnering and collaboration involves coordinated efforts at the national, state, and local levels, and sharing of resources across and within these tiers. Organizations at all levels have produced materials and approaches that help to bridge the information gap for these populations.

Information providers who are attempting to serve special populations emphasized the importance of making connection with and working through community-based organizations that serve these populations, and encouraging these organizations to provide outreach and

information through established and trusted networks in these communities. Partnering activities we studied as part of REACH 2000 also suggest that the ROs are becoming more aware of the value of using local coalitions of non profit organizations to better reach some special populations, particularly the Hispanic and API populations. In South Florida, the RO has been featured as a guest on Hispanic radio talk shows addressing callers' Medicare questions. Activities in Seattle by the National Asian Pacific Center on Aging in conjunction with the RO, and the related translated materials there have been spreading to places like Houston and Philadelphia, and nationwide through the internet. The Seattle RO recruited a large coalition of API community organizations to work with it in planning and implementing a health fair targeted at API seniors. Coalition building offers a partnering strategy consistent with social marketing in that it provides an opportunity for CMS to not only educate partners about Medicare, but it provides an opportunity for CMS to listen and learn from coalition members about the special needs and behavioral barriers of the special population.

Appendix 1

The NMEP Community Monitoring Survey: Summary of Methods and Response Rates

The NMEP Community Monitoring Survey: Summary of Methods and Response Rates

The survey data in this report came from our NMEP Community Monitoring Survey, which was a telephone interview with beneficiaries in ten sites who were living at home. For this report we used data primarily from the six communities surveyed in 1998-2001. We excluded several groups, including those whose telephone numbers we could not find, those whose physical or mental impairments prevented telephone interviews, those with ESRD, and non-English speakers. In addition, a pilot administration of the survey yielded extremely low response rates for beneficiaries over 85 years of age. We excluded this age group from all subsequent administrations of the survey, so results generalize only to beneficiaries under the age of 86.

The 2001 sampling design differed in two important respects from earlier years. First, we added a sampling stratum for beneficiaries identified as non-white by CMS files.²⁸ Second, we added a sampling stratum for “involuntarily disenrolled” beneficiaries in Sarasota, Tucson, and four new sites whose managed care plans had terminated their coverage. As a result, beneficiaries in these over-sampled groups made up a much higher percentage of our sample than they did of the general beneficiary population. To produce estimates of population percentages, we weighted the data by the inverse of the sampling fraction.

We drew our samples from a complete list of beneficiaries living in each of the study communities. CMS administrative files provided the basis for this information, and we then matched telephone numbers for those who could be found in directories. One third of the beneficiary names and addresses did not yield telephone numbers, sometimes because beneficiaries were in institutions, and therefore not intended to be part of the survey. From 1998 to 2000 response rates ranged from 41 to 54 percent. This year 44 percent of eligible beneficiaries responded in the six study sites. Our total sample size for the 2001 survey was 2,986 beneficiaries, of whom 8 percent were disabled beneficiaries under the age of 65, 55 percent were aged 65-74, and 38 percent were aged 75-85. Total sampling sizes for previous years were 2,349 beneficiaries in 1998, 2,473 beneficiaries in 1999, and 2,382 beneficiaries in 2000.

The survey collected data about the sources beneficiaries turn to for information on Medicare, how well they are aware of, and understand some components of, the Medicare+Choice expansion, whether they need more information than they perceive to be available, whether they received and used the handbook, and their feedback on the handbook. We administered the survey in four waves: in Fall of 1998 (before mailing the handbook), and in the early months of 1999, 2000, and 2001 (after the annual handbook mailings were completed). This approach gathers information on changes in: awareness of some of the Medicare+Choice expansions; where beneficiaries go to find Medicare information; overall rates of information seeking; whether they are aware of the many information resources available to them; perceptions of the handbook; and satisfaction with its information.

²⁸ In all our analyses, we use beneficiaries’ self-descriptions to classify race and ethnicity. These sometimes differ from CMS’s classification, but most beneficiaries whom CMS identifies as non-white also describe themselves that way.

Questions that are new to the most recent implementation of the survey include questions on: how respondents describe their own information-seeking behavior, calls to 1-800-MEDICARE, the plan-comparison section of the handbook, and beneficiaries recognition of the terms “Open enrollment” and “Lock-in.”

For the 2001 survey, we attempted to contact 7,732 beneficiaries in the six sites covered by this report, and eventually obtained completed interviews from 3,041.²⁹ The contact procedure differed slightly this year from that used in the 2000 survey. In 2000, we terminated attempts to contact 461 (6 percent) of the 7,131 telephone numbers because the survey period ended before we had reached these persons. This year we made 20 attempts to reach every beneficiary. As a result, we contacted 6,112 individuals (79 percent of the telephone numbers selected for the survey). A total of 11 percent of the people we contacted (688) were ineligible for the interview because they were now institutionalized or deceased, or could not be interviewed because of language or other barriers. Assuming that the same proportion of the 1,620 we did not contact would also have been ineligible, we were left with an estimated 6,862 eligible beneficiaries to be interviewed. Of these, 2,383 (35 percent of the estimated eligible respondents) refused the interview and another 1,438 (21 percent of the estimated eligible respondents) were never contacted. We obtained completed data from the remaining 3,041 (55 of which said they were not on Medicare were not asked the remaining questions). As shown in Table B-1 these interviews represent 44 percent of the total number of estimated eligible beneficiaries that we attempted to survey. This is slightly higher than the response rate (41 percent of total attempts) obtained in 2000.³⁰

The cooperation rate for 2001 was 56 percent. In each year that we have conducted the survey, minorities and the oldest respondents have been consistently less likely to comply. This continues to be true in 2001. The patterns of cooperation are not significantly different from those of earlier years. In 2001, however, we did stratify the sample according to CMS’s records of the beneficiaries’ minority status. This allowed us to adjust the data so that minority respondents contribute to the sample estimates in the same proportion as they do to the total population. Thus a small source of bias that was present in the 2000 survey has been removed in 2001. This is unlikely to affect year-to-year comparisons. In 2000, CMS-identified minorities were 3 percent of eligible beneficiaries and 2.5 percent of respondents. Thus correcting for this bias has an effect between zero and ½ percent. In most cases the effect is completely invisible, because minority responses differ by only a small amount.

Appendix Table A.1
Response to Survey, by Wave

Survey Outcome	Survey Wave			
	1998 Baseline	1999	2000	2001
Responded	2,520	2,636	2,562	3,041
Not on Medicare	168	163	180	55
Ineligible	522	402	450	688
Refused	2,324	1,747	2,700	2,383
Never reached a person, eligibility unknown	893	478	958	1,620
Overall response rate	45%	54%	41%	44%
Overall cooperation rate	52%	60%	49%	56%

²⁹ This includes 55 whom we did not further interview because they said they were not on Medicare.

³⁰ In recalculating the response rates for 2000 we treated the 461 abandoned attempts as though we had attempted to contact the beneficiaries but never reached a person. In earlier years’ reports, these abandoned attempts were excluded from the calculations.

***Note: this table includes contacts with persons determined to be ineligible for interview.**

Source: Abt Associates' NMEP Community Monitoring Survey, a telephone survey of beneficiaries <86 years old.

Appendix 2

Literature Summary

Literature Summary

The limited knowledge of most beneficiaries about Medicare and health insurance is well documented. However, few researchers have examined 1) the role of information and its potential to impact beneficiaries' understanding and knowledge of Medicare, or 2) linkages between beneficiary knowledge and decision making in the context of Medicare program choices. Even less is known about whether and to what extent particular needs and barriers to information and knowledge may exist for populations with special information needs: who they are, what needs and barriers exist to their use of information, and how to effectively address them; what impact information supply and distribution may have on the knowledge and decision making of beneficiaries with special information needs; and how and to what ends the NMEP information campaign has addressed these issues. Further, there has been little if any systematic evaluation to assess the effectiveness of education and information interventions such as the NMEP to improve beneficiaries' knowledge, the effectiveness of specific messages, materials and channels in reaching various beneficiary groups, and the role of information providers in addressing information supply at the local level.

Efforts to Define Special Populations for NMEP Information and Outreach: Few Attempts, Limited Evidence or Available Data, and Lack of Consensus Among Experts.

For the NMEP, all Medicare beneficiaries have been identified as target audiences for Medicare information and outreach, consistent with the program's objective to reach out to beneficiaries in every community and household nationwide. From the inception of the program there has been general recognition that certain groups would require special sensitivity for their information needs to be addressed. Defining these groups has been a difficult task.

Establishing useful profiles and segmentation strategies to guide information and education activities has proven equally challenging. Research about beneficiaries' decision making and its relation to information needs, knowledge, and behavior for the general Medicare population, overall, is sparse. Some studies address Medicare beneficiaries and their information needs, knowledge, and use describes findings for the general population of beneficiaries, derived from general surveys of Medicare populations and focus groups. However, little information is available about the specific issues confronting sub-groups of the beneficiary population. Survey data for analyses of special populations have not been widely available to assist detailed examination of beneficiary sub-groups, and focus groups have been employed only on a limited basis. Reports about special populations are often anecdotal, leading to ad hoc identification of special populations, their characteristics and needs.

Policy experts, researchers and others have made several efforts to identify segments within the Medicare population that may have information needs that require special attention. These efforts have focused on several types of criteria: 1) groups considered vulnerable due to their ethnic minority status or low income, thought vulnerable due to consequences of poor choice that may have consequences for cost, access, and quality of health services; 2) groups considered vulnerable due to cognitive or physical deficits to comprehension, or low literacy; 3) groups considered vulnerable due to cultural and linguistic disadvantage dealing with the healthcare system; and 4) groups considered vulnerable due to geographic or physical isolation (e.g., rural residents and homebound individuals) for whom choices and information channels are generally limited. Studies cited widely in policy discussion about Medicare+Choice information are summarized in the text and in Table A.2 at the end of this section.

The Institute of Medicine (IOM). The Institute of Medicine Committee on *Developing an Information Infrastructure for the Medicare+Choice Program*³¹ is one of the most comprehensive attempts to identify and describe populations with special information needs for the NMEP. The IOM work groups considered several approaches to targeting information activities to Medicare beneficiaries to address their diverse information needs. While there was no agreement about the preferred approach, several strategies were considered. Committee members considered including segmenting the population into at least two groups: persons 70 years of age and younger, and persons older than 70 years of age (based on their different levels of activity and information capabilities, e.g., younger beneficiaries tend to be more active and Internet savvy). Other suggestions addressed segmenting beneficiary groups by health status.

The IOM Committee considered CMS's general categories of frail elders: those with low levels of education, African Americans, rural residents, persons with impaired hearing or vision, Hispanics, and dual-eligibles (persons eligible for both Medicare and Medicaid). The Committee also considered the following sub-groups of the overall beneficiary population that require special sensitivity for NMEP information and outreach:

- **Chronically ill individuals in managed care:** Presentations were mixed on how managed care organizations address individuals with chronic illness. The Committee was told that these beneficiaries tend to be happier with their primary care provider if they feel comfortable with that person and that they also rate their satisfaction with a health plan higher if they do not use it very much.
- **Immigrants for whom English is not their primary language and those with low literacy:** Immigrants over age 65 come from diverse cultures and speak different languages. Presentations noted that 12 percent of Americans over age 65 speak a language other than English; of these, 30 percent speak Spanish. Over the last three decades the largest number of immigrants have come from China, Mexico, the Dominican Republic, Jamaica and India. In addition to language barriers, immigrants face the same barriers to understanding and choosing a health plan as native born beneficiaries, as well as economic and legal barriers to care. Many come from countries with oppressive regimes, and are distrustful of government. These populations have different cultural approaches to health and healthcare, and tend to have lower levels of literacy, particularly written English.
- **Cognitively impaired individuals:** The Committee heard differing estimates of this population. According to the Medicare Current Beneficiary Survey (MCBS), 5 percent of beneficiaries have Alzheimer's disease and 2 percent have mental retardation. However, the Alzheimer's Association estimates that 10-15 percent of the Medicare population have some form of dementia, and another 4-6 percent have mental retardation. With these populations it is important to make sure family members are provided with good information.

Kleimann Communications Group. Kleimann takes a broader view, citing seniors' difficulties processing information relating to cognitive and physical challenges, limited literacy and

³¹ Institute of Medicine, *Developing an Information Infrastructure for the Medicare+Choice Program: Summary of a Workshop*, Washington, DC: National Academy Press, 1999.

language capabilities, and other changes associated with the aging process that expand definitions of vulnerability to include the majority of Medicare beneficiaries. Reporting findings from focus groups in English, Spanish, and Chinese she conducted with the National Academy of Social Insurance and the California Health Care Foundation and related studies at Senate hearings and IOM work groups, Kleimann suggests that most seniors suffer “information overload,” are not active information seekers, and need “usable” information to make decisions, not merely the right information and not merely all of the information. Kleimann recommends information targeted to specific audiences CMS is trying to reach, with particular attention to vulnerable groups—a majority of the beneficiary population.

“Active, informed consumers can take care of themselves. Too much information is, for most beneficiaries, wasted time and effort. [CMS] needs to worry about the vulnerable population—people who cannot sort through mounds of definitions and facts and figures, and who will be overwhelmed by too much information. Unfortunately, this is probably 98 percent of the beneficiaries. For people with low literacy skills, cognitive impairments, problems with vision, people who do not speak English or do not feel comfortable dealing with complicated issues in English, understanding Medicare options will be especially intimidating.”

Barents Group. In the early stages of the NMEP campaign, Barents Group³² prepared for CMS market research profiles that focus on the information needs and effective communication strategies for the general Medicare population age 65 and older and not living in a long term care facility. Data were obtained from three sources: 1) an inventory of “best communication practices” from a variety of organizations and individuals who work with Medicare beneficiaries, 2) focus groups with Medicare beneficiaries, and 3) a national survey of the Medicare population (MCBS). Profiles were produced for:

- General Medicare beneficiaries
- African American beneficiaries
- Hispanic American beneficiaries
- Beneficiaries who are dually eligible for Medicare and Medicaid
- Beneficiaries who live in rural areas
- Beneficiaries with vision impairments
- Beneficiaries with hearing impairments, and
- Beneficiaries with a limited education or low literacy skills.

Beneficiaries “about to enroll” were also selected for special study but work had not been completed on this profile at the time their report was completed.

Barents Group does not provide rationale for sub-group profiling. However, this research provides detailed descriptions of beneficiaries’ knowledge, information preferences and use for each sub-group. Barents’ research also considers beneficiaries’ information seeking behavior—as proactive, reactive, or passive information seekers—as important factors for segmenting all profiled groups.³³

³² Barents Group LLC in affiliation with Project HOPE-Center for Health Affairs, and Westat, Inc., *CMS Market Research for Beneficiaries*, April 1999.

³³ The active-passive-reactive model is described in a subsequent section of this review.

Neuman and Langwell. Neuman and Langwell³⁴ build on these and other findings in a recent policy article on beneficiary knowledge, information needs, and vulnerable status that suggests that a significant proportion of beneficiaries will not make good choices—and could face potentially serious financial and access problems in the Medicare+Choice program. The authors cite findings from recent surveys and focus groups that show a significant proportion of beneficiaries may have difficulty *obtaining* as well as *understanding* information about Medicare.

Neuman and Langwell suggest that beneficiaries with diverse needs, circumstances, and certain limitations may have difficulties in the new Medicare marketplace. For example:

1. Beneficiaries with limited education, serious limitations in cognitive functioning, and those in relatively poor health who may find information confusing and difficult to use—as high users of healthcare services they may face serious consequences if care is disrupted, if they lose access to specialists, or cannot afford care they need.
2. Low income beneficiaries who may not have the financial resources to choose based on quality, access to doctors, or benefits—as consumers whose choices are likely to be dictated by price, they may face disruptions in care, poorer quality of care, and lower levels of satisfaction, and are likely to be disproportionately affected by plan premium increases.
3. The most economically disadvantaged beneficiaries who may be eligible for both Medicare and Medicaid, and managed care under both programs—as consumers dependent on information about eligibility and coordination of program benefits, they may face difficulties navigating the system to enroll in and receive entitlements.

Several Population Sub-groups Identified with Special Information Needs Also Experience Disadvantage in Health and Economic Status, and Access to Services.

While there is no consensus about how best to define and segment populations with special information needs, there is strong evidence that many sub-groups identified as populations that many require special sensitivity in the NMEP also experience disadvantaged health and economic status and access to services. Research by MedPAC, the Henry J. Kaiser Family Foundation, and the Commonwealth Fund have been widely cited in policy discussion and literature. These analyses examine characteristics of vulnerability among some minority sub-groups of the Medicare population. These studies, directed to other Medicare monitoring concerns, do not link findings to information needs or approaches, and do not address the potential role of information and education in helping to overcome barriers to informed choice. However, they do illustrate show areas of potential vulnerability and consequences that may be associated with health insurance options for many of the sub-groups identified as populations with special information needs under the NMEP.

³⁴ Neuman, P. and K. Langwell, “Medicare’s Choice Explosion? Implication for Beneficiaries,” *Health Affairs* vol. 18, no. 1, January/February 1999: pp. 150-159.

MedPAC. Analyses by researchers at MedPAC³⁵ show that certain beneficiary characteristics and circumstances are associated with a greater likelihood of experiencing problems in obtaining needed health care on a timely basis. These analyses use data from the 1998 Medicare Current Beneficiary Survey to identify groups of beneficiaries who have been found to be vulnerable to access problems in traditional Medicare that appear to be related to minority status, relative need for care, and ability to pay for care. MedPAC's analyses show that African Americans, Hispanics, and beneficiaries who are functionally disabled, in poor health, poor, or lacking supplement insurance were more likely to experience service access problems. In contrast, Medicare managed care enrollees' access to services varied based on health, functional or disability status rather than on race, ethnicity or income. Evidence of access problems for rural beneficiaries was mixed, complicated by rural residents' patterns of service utilization, and changes in provider reimbursement in these areas.

MedPAC analyses for 1998 also show that rural residents and the disabled showed the largest disparities between Medicare+Choice and the traditional program. Relatively high levels of access problems were also found among beneficiaries without supplemental coverage. These beneficiaries were more than three times as likely to have delayed care due to cost, more than three times as likely to lack a usual source of care, and more than two and a half times as likely to have not visited a doctor's office in the past year, compared with those with supplements.

Beneficiaries in traditional Medicare, overall, were overwhelmingly satisfied with their health care in 1998 (results consistent with prior community analyses), but certain groups of beneficiaries were less likely to be satisfied, although levels of satisfaction were very high even among these groups. Beneficiaries in fair or poor health, those needing assistance with functional impairment, disabled beneficiaries, and those without supplementary insurance were less satisfied with their health care. Decreased satisfaction with quality was found among Hispanics, those with annual incomes below \$10,000, and urban residents.

Henry J. Kaiser Family Foundation. The Henry J. Kaiser Family Foundation³⁶ examined disadvantage in health and economic status, health insurance, and access among minority beneficiaries compared to majority beneficiaries, providing similar evidence of the associations described by MedPAC. According to Kaiser Foundation analyses³⁷:

- Minority Americans suffer from more illnesses and are more apt to live in poverty, and face greater risk of access problems and financial burdens related to medical care. More than 40 percent of African American and Latino seniors perceive their health status as fair or poor, compared with 25 percent of whites. More than 1 in 6 has functional limitations (compared with 1 in 10 whites). Minority beneficiaries

³⁵ MedPAC, *Annual Report to Congress*, March 2000.

³⁶ Henry J. Kaiser Family Foundation, "Medicare and Minority Americans," *The Faces of Medicare*, www.kff.org.

³⁷ The Kaiser Foundation reports that minority Americans will more than double as a share of the elderly population, and will account for one in three Medicare beneficiaries by 2025. Currently, this group accounts for approximately 14 percent of the nation's elderly and 16 percent of the total Medicare population, more than half of whom are African American. Latinos are the next-largest group, and Asian Pacific Islanders, American Indians, Eskimos and Aleuts account for less than 2 percent. By 2025, Latinos will account for 18 percent of the minority elderly population, blacks for 10 percent, and other races for the remaining 7 percent.

are more likely than whites to report having cognitive impairments such as dementia; men and women report cognitive problems in equal proportions.

- About a third of minority beneficiaries live below the poverty level—more than three times the share of whites. Nearly two-thirds of African American and Latino beneficiaries have incomes below twice the poverty level, compared with 41 percent of whites.
- Minority beneficiaries are more likely than whites to rely solely on the traditional Medicare program for insurance coverage. About a quarter of African American and Latino beneficiaries have no supplemental coverage, compared with 10 percent of all whites. Two-thirds of all white beneficiaries have Medigap or employer-sponsored retiree benefits, compared with only a third of African Americans and a quarter of Latinos. African Americans and Latinos are more likely than whites to rely on Medicaid to supplement Medicare.
- African Americans are more apt to encounter problems getting needed care than white beneficiaries; disparities in use of services among whites and other minorities are well documented.

Findings from the pre-NMEP Kaiser Family Foundation/Commonwealth Fund *1997 Survey of Medicare Beneficiaries*,³⁸ a nationally representative sample of 3,309 beneficiaries, showed that Medicare beneficiaries gave high ratings to the program, with 57 percent “very satisfied.” Despite relatively high rates of health problems among the elderly and disabled, fewer than five percent of all beneficiaries said they did not get needed care, and 15 percent reported difficulties getting needed care. Access and cost problems were more common among those with low incomes and health problems. Nearly two of five beneficiaries with incomes below the poverty level, in fair or poor health, or who need help with daily activities experienced problems getting needed healthcare or paying medical bills. Beneficiaries lacking supplemental coverage were more likely to experience problems with access and cost.

These studies highlight the potential for adverse health consequences of healthcare coverage decisions for many vulnerable sub-groups of the Medicare population. MedPAC is monitoring these trends, with special studies planned of rural beneficiaries. These minority sub-groups, while significant in number, represent only those who can readily be identified by national data sources, and represent only a subset of potentially vulnerable beneficiaries.

Knowledge of Medicare is Limited Among General Beneficiaries—Little is Known About Knowledge Among Beneficiary Sub-groups.

It is well documented that knowledge of Medicare and health insurance among beneficiaries, overall, is limited. Much of the evidence in this area is based on analysis of survey data and focus groups. Case studies and anecdotal reports from the field also report these findings. Only a few studies have been conducted of sub-groups of Medicare population, including potentially vulnerable segments, although issues concerning special populations have emerged

³⁸ Schoen, C. et al, *Medicare Beneficiaries: A Population at Risk: Findings from the Kaiser/Commonwealth 1997 Survey of Medicare Beneficiaries*, The Henry J. Kaiser Family Foundation and The Commonwealth Fund, December 1998.

continually in site monitoring work and studies of populations with special needs for CMS and national healthcare foundations.

Few studies have addressed beneficiary sub-groups and their knowledge and use of Medicare information. Of these, one series of reports has advanced understanding of these areas considerably and deserves particular mention. Under grant funding from CMS, the *Medicare Beneficiary Grassroots Rights and Protections Outreach Project for Vulnerable Populations*,³⁹ conducted by Pro-West, National Asian Pacific Center on Aging (NAPCA), National Indian Council on Aging, and RAND, addresses a range of information use issues in racial and ethnic communities. This set of studies includes community surveys, focus groups, needs assessments, environmental scans, and a comprehensive bibliography on minority seniors' needs and use of information relevant to the NMEP's information and outreach activities. These studies, the most comprehensive to date, identify significant information needs and issues among minority beneficiaries, and include specific studies conducted of Asian Pacific Islander (API) elders. While similar in-depth analyses do not exist for other beneficiary sub-groups, these studies provide useful models for data collection and study that may be adapted for other special populations.

We review findings from these and other studies below.

General Beneficiary Knowledge. Beneficiaries' confusion and lack of understanding of both traditional Medicare and managed care is well documented. Widely cited findings of surveys by CMS and the HHS Inspector General presented at 1998 Senate hearings on Medicare+Choice implementation show that:

- One-third of beneficiaries reported knowing little or nothing about original Medicare benefits or out-of-pocket payment for services.
- Over 40 percent reported knowing little or nothing about private supplemental insurance.
- About one-third of beneficiaries did not understand or know about appeals under Medicare.
- Six out of every ten beneficiaries reported knowing little or nothing about managed care.⁴⁰

Murray and Shatto⁴¹ published similar findings from MCBS data in the *Health Care Financing Review* later that same year. They reported that between 30-40 percent of beneficiaries knew little or nothing about traditional Medicare, such as what services are covered, out-of-pocket costs, and supplemental or Medigap insurance. More than half of beneficiaries felt they knew little or none of what they need to know about the availability and benefits of Medicare managed care plans.

³⁹ *Medicare Beneficiary Grassroots Rights and Protections Outreach Project for Vulnerable Populations*, prepared for CMS by Pro-West, National Asian Pacific Center on Aging, National Indian Council on Aging, and RAND, 1999.

⁴⁰ Testimony of M. Hash, op. Cit.

⁴¹ L. Murray and A. Shatto, "Beneficiary Knowledge of the Medicare Program," *Health Care Financing Review*, vol. 20, no. 1: Fall 1998, pp. 127-131.

Hibbard and Jewett⁴² provide the most comprehensive and widely cited investigation of beneficiaries' knowledge and understanding of Medicare and managed care to date. In a phone survey conducted for AARP Hibbard and Jewett evaluated knowledge levels among 1,673 beneficiaries residing in five Medicare markets with high managed care penetration, half of whom were enrolled in managed care plans and half in the traditional Medicare program. Findings show that 30 percent of their respondents knew almost nothing about managed care plans; only 11 percent had adequate knowledge to make an informed choice; and managed care enrollees had significantly lower knowledge levels of the differences between the two delivery systems. The study found that the most significant predictors of knowledge were income and education. Enrollees reported lower incomes and lower levels of education than did enrollees in traditional Medicare. Those exercising choice were often the least well able to make key distinctions between traditional Medicare and Medicare managed care organizations. This sample is said to represent a general Medicare population.

Hibbard and Jewett also tested respondents who demonstrated some minimal knowledge of managed care plans to assess whether they could distinguish the characteristics of plans from those of Medicare fee-for-service. The average knowledge score among test takers was 56 percent correct, with test takers enrolled in traditional Medicare scoring higher than test takers enrolled in managed care plans. Among the sample of test takers, only 16 percent had adequate knowledge to choose between traditional Medicare and a managed care plan, more than 41 percent scored in the inadequate range, and 7 percent scored in the lowest quartile (equal to or worse than guessing). Those who scored in the lowest quartile were more often female, enrolled in a managed care plan, used fewer information sources, had less education, and had a lower income level than those in the highest quartile. Those test takers with the highest knowledge scores were likely to be males, traditional Medicare enrollees, those who used more information sources, and those with higher education and higher income.

These findings are mirrored in other surveys and focus groups that indicate most beneficiaries do not understand the basics of traditional Medicare fee-for-service, and understand even less about Medicare+Choice options.⁴³ In their review of expanded choice for Medicare beneficiaries, Neuman and Langwell⁴⁴ cite findings from several studies, including the Kaiser Family Foundation/Harvard School of Public Health's *National Survey on Medicare*. Results of this survey show that 37 percent of Americans age 65 and older do not know that traditional Medicare does not cover outpatient drugs, 56 percent do not know that Medicare does not cover long term nursing home care, and about a quarter of elderly Americans are aware of Medicare+Choice but only 9 percent understand that it provides beneficiaries with a greater choice of health plans, rather than a greater choice of doctors.⁴⁵ Neuman and Langwell also cite

⁴² J. Hibbard and J. Jewett, *An Assessment of Medicare Beneficiaries' Understanding of the Differences Between the Traditional Medicare Program and HMOs*. Public Policy Institute and American Association of Retired Persons, Washington, DC, 1998; Hibbard et al, "Can Medicare Beneficiaries Make Informed Choices?" *Health Affairs*, vol. 17, no. 6, November/December 1998: pp. 181-193.

⁴³ Hibbard et al, 1998; Frederick Schneiders Research/Kaiser Family Foundation, 1998; DHHS/OIC, 1996, cited in Neuman and Langwell, "Medicare's Choice Explosion? Implication for Beneficiaries," *Health Affairs*, vol. 18, no. 1, January/February 1999: pp. 150-159.

⁴⁴ Neuman, P. and K. Langwell, *ibid*.

⁴⁵ Henry J. Kaiser Family Foundation/Harvard School of Public Health, *National Survey on Medicare*, cited in Neuman and Langwell, *op. Cit*.

findings by Barents Group that show minority groups are less likely to understand basic elements of the Medicare program—one of the few studies to examine these issues for minority sub-groups.

A recent study of health plan choice among Medicare and non-Medicare groups by Hibbard et al.⁴⁶ shows that more than half of Medicare beneficiaries had difficulty interpreting comparative health plan data. Beneficiaries made almost three times as many errors interpreting this information (25 percent vs. 9 percent) as younger respondents, and demonstrated greater variability, largely in the area of comprehension. Among the Medicare sample, those in poorer health, with less education and older tended to make more errors. Comprehension performance declined after age 80—about four times the number of errors made by beneficiaries 65-69 years of age. The authors suggest that lower performance in older age groups is not just a literacy effect but an aging effect as well. Those with poorer comprehension skills were also more likely to indicate a desire to delegate decision making about their healthcare coverage.

Findings of a telephone survey of Medicare beneficiaries conducted in 2000 by Mathematica Policy Research⁴⁷ are also consistent with those of previous studies which show that Medicare beneficiaries have relatively limited understanding of the basics of Medicare. Knowledge about Medicare was also found to be low among family members and others likely to be advising Medicare beneficiaries, although informal sources of information dominated beneficiaries' decision making—mostly through spouses, family, friends, or medical professionals.

The survey also found that formal infrastructure locally supporting choice reaches only a minority of beneficiaries. Only 19 percent of all beneficiaries say they knew of “a local service in their area that offers free and unbiased counseling” to people on Medicare about choosing a health insurance plan, and another 29 percent said they would be somewhat likely to use it.

Vulnerable Medicare sub-groups are less satisfied with their current coverage and more worried about healthcare expenses.⁴⁸ Both poor health and socio-economic vulnerability increase the likelihood that a beneficiary will consider choice. Findings on the process and information used in choice differ by sub-group. Gold *et al.* report the following findings (p.xxvii, *ibid.*):

- The under-65 disabled. The needs of this sub-group do not appear to be well served by the current infrastructure, which tends to be modeled around the needs of the elderly and the organizations actively engaged in working with them. Reaching the under-65 disabled probably requires a strategy targeted to this sub-group and its specific concerns (for example, issues related to employment-based coverage, options when individuals are dually

⁴⁶ Hibbard, J. P. Slovic, E. Peters, M. L. Finucane, and M. Tusler, “Is the Informed-Choice Policy Approach Appropriate for Medicare Beneficiaries?” *Health Affairs*, Vol. 20, No. 3, May/June 2001: pp. 199-203.

⁴⁷ Gold, M., M. Sinclair, M. Cahill, N. Justh, and J. Mittler, *Medicare Beneficiaries and Health Plan Choice, 2000*. Robert Wood Johnson Foundation, January 2001, 120 pp.

⁴⁸ Survey analyses focus on: under-65 disabled, those 85 years of age and older, low and moderate income beneficiaries, those with limited education, African Americans, those of other races including Asians, Hispanics, those in fair or poor health, those with various disabilities that lead them to need assistance, and those who are unable to answer the survey directly but need a proxy.

eligible for Medicare and Medicaid, and coverage issues associated with specific health care needs linked to various disabilities.)

- **The “oldest old.”** Those 85 and older find choice less salient than others, perhaps because of an aversion to change since they are no less satisfied with their current plan than are others. CMS’s current strategy of written information and web-based communication seems well targeted to the needs of informal advisors to these beneficiaries (as judged by responses of proxies). However, more extensive and clearer information on choices and access to one-on-one advice would be useful.
- **Lower-education and/or income.** CMS’s current strategies do not seem to reach lower-income beneficiaries as effectively as they reach higher-income individuals. In reaching out to those with lower incomes or less education, CMS and others would be well advised to take into account that those beneficiaries heavily rely on their personal physician in making a choice. Physicians typically may be pressed for time and could have a vested interest in steering individuals to certain choices. Reaching out to physicians and helping them give effective advice could be a useful strategy. However, gaining physician cooperation might be a challenge given the many demands on physicians’ time. Perhaps a practical strategy would be to provide physicians with leaflets that they could distribute to patients, outlining information on choices and where to get neutral information on the choices in their community.
- **Racial and ethnic minorities.** The experience varies across sub-groups; however, those who are not white or of Hispanic background rely less on personal physicians or their current plans, perhaps because these beneficiaries are less likely to trust their physicians, have a less personal relationship with them, or have no current source of supplemental coverage. The *Medicare&You* handbook, as well as the Internet, are used less. A key strategy to reach racial and ethnic minorities should include in-person meetings and one-on-one advice. Current structures reach African Americans better than other minority sub-groups. Both survey and site visit results suggest that reaching Hispanics and those of “other” races will require close work with community organizations trusted by these sub-groups.
- **Poor health or functional needs.** Choice is very salient to those in poor health or with functional needs. The findings suggest, however, that many individuals in poor health or with functional disabilities are socially isolated. They typically do not rely extensively on family or friends and, despite their greater need, seem no more likely than the average beneficiary to use government sources of information. Reaching them probably requires a combined effort to work with physicians (because those in poor health see physicians more than do beneficiaries in good health) and to address the access barriers that make it harder for them to use available sources of unbiased counseling (for example, mobility problems for the homebound).

Most Beneficiaries Do Not Want or Need All Information—Information Should Be Targeted to Specific Needs and Preferences, but Little is Known to Guide Efforts for Beneficiary Sub-groups.

Despite obvious gaps in knowledge and understanding of Medicare and their Medicare+Choice plan options, studies show that most beneficiaries do not want and are not able to absorb all

information.⁴⁹ The majority of beneficiaries do not use formal information on quality of care provided by health plans, providers, or other organizations. Further, people cannot always anticipate their needs for information.⁵⁰ Most studies on this topic do not address beneficiary sub-groups, although some suggest the importance of segmenting elderly consumers according to their information preferences, and recommend strategies with potential for application to NMEP information activities.

Bernstein and Gauthier,⁵¹ in a recent examination of consumer choice in health care, note that preference functions--what people value and how this translates to choice from among available options--and information affect consumers' actual choices, but do not determine what choices are available. Available choices are usually determined by others, e.g., employers, the market, geography or the government. The choice set is also affected by personal characteristics, such as the ability to pay for a more expensive plan or providers not included in a network or to relocate to an area with a greater selection of providers, or even lifestyle.

Studies also show that consumers process information and make decisions about health care coverage in different ways. A 1994 review of research by RTI, HER and Benova that addresses consumers' knowledge, needs, and decision making processes related to comparing and choosing health plans concluded that most consumers have a basic understanding of their health plan options but much less understanding of the more detailed and complex issues involved.⁵² Few studies looked at or documented beneficiary sub-group differences, and those that did reported only that knowledge tended to be higher among persons with higher education, those more experienced with their healthcare system, and those who receive more information.

Site monitoring findings by Mathematica Policy Research⁵³ suggest that Medicare beneficiaries try to understand only as much as is directly relevant to their circumstances and rarely seek information unless there is some kind of change of circumstance or crisis, whether internal or external to their own lives. Most make decisions on the basis of the most basic information about the cost of coverage, whether their physician is in the plan, and whether there is coverage for prescription drug needs.

Similar findings have been reported by Abt Associates'⁵⁴ monitoring of NMEP information activities for CMS during 1998 and 1999. These activities found that most Medicare beneficiaries are passive and non-analytical consumers of health insurance information. Site monitoring showed:

⁴⁹ Kleiman, 1998; Hibbard, 2000; Edgeman-Levitan, Cleary, 1996

⁵⁰ J. Lubalin and L. Harris-Kojetin, "What Do Consumers Want and Need to Know in Making Health Care Choices?" *Medical Care Research and Review*, vol. 56 Supplement 1 (1999), pp. 67-102.

⁵¹ Bernstein and Gauthier, "Choices in Health Care: What Are They and What Are They Worth?" *Medical Care Research and Review*, vol. 56 Supplement 1 (1999), pp. 5-23.

⁵² J. Lubalin and L. Harris-Kojetin, op.cit.

⁵³ B. Stevens and J. Mittler, *Making Medicare+Choice Real: Understanding and Meeting the Information Needs of Beneficiaries at the Local Level*, Mathematica Policy Research for the Robert Wood Johnson Foundation, November 2000.

⁵⁴ "Assessment of the National Medicare Education Program," Fact Sheet, CMS, www.medicare.gov/nmep/publications&reports/pdfs/fctsht.pdf.

- Beneficiaries believe strongly that “if it ain’t broke, don’t fix it,” and will stick with an existing arrangement as long as possible, until something happens that makes continuing with the *status quo* impossible. They tend to fear change, and worry about their ability to understand and cope with it.
- Beneficiaries tend to seek information only when specific needs arise. Few try to routinely follow developments in the health insurance world to learn of changes that may impact them or of coverage options that may be superior to their current arrangements.
- When beneficiaries do seek information to resolve a particular problem, they generally want to be told what is the best course of action for their situation, not to be given complicated information to analyze on their own or advice on how to go about thinking about the problem.
- When beneficiaries seek information, they tend to have a limited “information horizon.” For example, if they need to switch to a new plan, and are aware of a plan with which a friend is happy, they will switch to that plan without conducting a search for additional options. Indeed, it may not even occur to them that the other options may exist, or that they should be conducting a comprehensive search to see whether additional options exist or not. One of the most important sources of information for beneficiaries is managed care plans—marketing information provided prior to enrollment, often unsolicited or solicited in response to advertising, and customer help lines provided to enrollees. Beneficiaries are typically unaware or only vaguely aware of independent sources of information, and are usually not motivated to find and use such sources.

Grey Advertising,⁵⁵ under contract to CMS, introduced segmentation based on beneficiaries’ information seeking behavior at CMS’s REACH planning sessions in February 2000 as a possible framework to assist Regional Offices and partners in their efforts to target and segment beneficiary groups for Medicare information and outreach. Grey suggests that beneficiaries’ information seeking styles can be segmented into three categories: proactive, reactive, and passive. Multiple factors, including other target audience characteristics, affect an individual’s search style.

Barents Group. Using this same framework, Barents Group reports that beneficiaries differ in their approaches to gathering information, suggesting additional segmentation among demographic groups profiled for the study. This research shows:

- A minority of beneficiaries appear to *proactively* gather information.
- A second, and much larger, group of beneficiaries tend to seek information as it is needed, in a *reactive* mode.
- A large number of beneficiaries appear to be *passive* information seekers.

⁵⁵ Grey Advertising, “Information Seeking Behaviors—Applying a New Framework to Better REACH our Communities,” REACH Planning Conference, Baltimore, MD, February 16, 2000.

Barents focus groups suggest that beneficiaries' preferred sources of information and preferred communication modes for obtaining that information often depend on 1) the topic and 2) a beneficiary's information-seeking behavior:

- Written materials (e.g., pamphlets, the Medicare Handbook) tend to be good sources of information for people with proactive search behavior, who often choose detailed printed material that they can review thoroughly and refer back to when needed.
- Beneficiaries with specific and immediate information needs who reactively seek information generally prefer interactive communication formats (e.g., telephone hotlines, the Internet, one-on-one counseling through SHIPs) where they can hone in on the particular information they need without having to wade through a lot of perceived extraneous material. Printed material is also valuable for reactive information seekers when they can refer to the material to answer a specific question through an easily accessible format.
- Beneficiaries who are passive information seekers are best served by interactive modes for all types of Medicare information. They are also likely to benefit from information strategies that involve diverse media (e.g., TV, radio, hot lines), formats (e.g., written and audio), and channels (e.g., through local TV and radio stations, through community organizations such as senior groups, churches and civic organizations, and through SHIPs). Disseminating information through a variety of sources and channels increases the chance that passive information seekers will come upon the information they need.

Barents' research indicates that beneficiaries have three types of information needs: 1) basic information needs, such as whether and how to enroll in various Medicare options; 2) navigational information needs, such as how to make the best choice among plans or providers, how to access specialists or preventive services; and 3) situation-specific information needs, such as locating a participating physician in an area, whether coverage for specific services or equipment is provided, or out-of-pocket costs associated with specific healthcare needs.⁵⁶

Beneficiaries' needs and preference structures have been found to evolve over time.⁵⁷ Barents Group provides a practical illustration. As beneficiaries enter the program, gain experience with the Medicare system, and continue to age, their health and information needs change, moving through several stages and decision points. Beneficiaries may require different types of information to inform different sets of decisions associated with each stage. Beneficiaries are likely to require basic Medicare information at *pre-enrollment*, to help inform their decision making about whether, when and how to enroll in Medicare. At the time of *enrollment*, beneficiaries may need different, more detailed information, enrollment information, and information about availability of information and counseling services to assist their Medicare coverage selection. As Medicare *users* after enrollment, beneficiaries' needs are likely to shift to information about Medicare services, providers, premiums and co-pays, and appeals to help guide their choice, use and payment of services. Beneficiaries may also need information at times when they *reconsider enrollment* regarding disenrollment and transfer processes, including reexamination of their options from among available choices.

⁵⁶ Barents Group, *ibid.*, p. 3.

⁵⁷ Barents Group, *ibid.*, and Lubalin and Harris-Kojetin, *op.cit.*

Recent work by Pro-Change Behavior Systems,⁵⁸ conducted under contract to CMS, offers additional insight to help guide NMEP information activities. Pro-Change adapts the Trans-theoretical Model (TTM) of health behavior change to explore applications of stages of change—pre-contemplation, contemplation, preparation, action, and maintenance—as a possible foundation upon which to build interventions to increase participation in informed health plan choice among Medicare beneficiaries. Pro-Change developed three staging algorithms based on the MCBS and questions developed for this project to be included in Round 23 of the MCBS to assess beneficiaries’ readiness to engage in three types of informed choice: 1) learning about the Medicare program, 2) learning about Medicare managed care plans, and 3) reviewing different health plan options.

Study analyses show that beneficiaries are furthest along in their readiness to learn about the Medicare program (44 percent of respondents are in the Action stage). Beneficiaries are less ready to learn about the availability and benefits of managed care plans (27 percent in Action) and to review different health plan options (12 percent in Action or Maintenance). Beneficiaries’ stage of change was related to knowledge about the Medicare program, information seeking, and most other variables (e.g., income and education) expected to vary with stage. Beneficiaries in the later stages scored significantly higher on five measures of Medicare knowledge than did beneficiaries in the earlier stages of change, and were more likely to seek out and find information on new benefits, services covered, and managed care plans. Pro-Change reports that 1) stage of change for learning about the Medicare program was a better predictor of knowledge about the Medicare program than all demographic, health status, and health plan variables examined, even education; and 2) stages of change for learning about Medicare plans were the best predictors of knowledge about Medicare managed care plans. Research to further application of this approach is underway. It is not yet known how these stages may differ across beneficiary sub-groups.

CMS and its contractors at the Center for Health Systems Research and Analysis and Research Triangle Institute⁵⁹ have also been conducting studies to develop an index for measuring beneficiaries’ knowledge of specific areas of Medicare. This research is intended to expand the capabilities of the MCBS to track, monitor and inform Medicare information and education activities, and to provide measures for continuous program improvement in these areas.

Are There Barriers to Knowledge? Are Beneficiary Sub-groups Differentially Affected, and Do They Need Special Consideration in the NMEP Information Campaign?

The research literature cites many factors that suggest barriers to knowledge exist among beneficiaries. These generally focus on characteristics of beneficiaries or beneficiary sub-groups that may disadvantage their ability to access or use mainstream information sources or services. Some limited attempts have been made to estimate the extent or size of certain beneficiary sub-groups that may experience such barriers using the MCBS and other secondary data sources. Other evidence is drawn from focus groups and site monitoring studies.

⁵⁸ Pro-Change Behavior Systems, Inc., *Assessing Readiness of Medicare Beneficiaries to Participate in Informed Health Care Choices*, Contract No. 17-C-90950/1-01, October 12, 2000.

⁵⁹ C. Bann et al, *Analysis of Medicare Beneficiary Baseline Knowledge Data from the Medicare Current Beneficiary Survey: Knowledge Index Technical Note*, CMS Contract No. 500-95-0061/004, May 5, 2000.

Most studies focus on characteristics of beneficiaries themselves as barriers to knowledge and understanding of Medicare. Studies address factors such as physical and cognitive deficits, cultural and language differences, and literacy levels are widely cited barriers. Several surveys and recent studies examine the inherent difficulties of using education and information campaigns to increase beneficiaries' knowledge for informed choice, given the limitations in capability of most seniors. Dallek⁶⁰ and others cite findings of the National Adult Literacy Survey (1992) that shows as many as 53 percent of elderly Americans cannot read. Physical conditions and cognitive difficulties associated with aging are also barriers to beneficiaries' knowledge and understanding. According to Moon's recent analyses of MCBS data,⁶¹ nearly one-fifth of Medicare beneficiaries was in poor physical health in 1993, and nearly a quarter of all Medicare beneficiaries have problems with cognitive functioning, including mental retardation, mental disorder, Alzheimer's disease, or difficulties handling money or talking on the phone. Moon estimates that 31.6 percent of all beneficiaries have one or both types of impairments that are likely to compromise their ability to understand key differences between plans or make good choices.

Barriers to knowledge and information may be acutely experienced by minority populations who face cultural and linguistic challenges dealing with Medicare, government and healthcare systems in general. Yee⁶² provides an extensive bibliography of studies relevant to these issues for Asian and Pacific Islander (API) and other cultural and linguistic minority elders produced under contract to CMS as part of the *Medicare Beneficiary Grassroots Rights and Protections Outreach Project for Vulnerable Populations*. This project also includes assessments of needs and barriers to Medicare information and services in API communities.

In one study, Yee and Shin⁶³ surveyed 3,500 API elders and community leaders at town hall meetings and round tables in five communities in Washington State to obtain information on API elders' experiences getting information about gaining access to needed health and social service programs. Findings indicate that the areas elders believe to be most problematic were: 1) language access, 2) enough money to live on, 3) affordable housing, 4) transportation availability, and 5) employment. In a second study conducted over two years in Los Angeles County, Seattle, Philadelphia, Boston, Chicago, San Francisco Bay Area, and New York City, more than 4,000 API elders ranked 1) lack of information about services, 2) language barriers, 3) access to health information, 4) health services, 5) transportation among their most pressing concerns. The authors note that these results are similar to those of the previous study, especially in ranking of the top five problems: information, poverty, language, loneliness, and transportation.

⁶⁰ Testimony of Geraldine Dallek, Institute for Health Care Research and Policy, Georgetown University, Special Committee on Aging, U.S. Senate, May 6, 1998.

⁶¹ M. Moon, "Will the Care Be There? Vulnerable Beneficiaries and Medicare Reform," *Health Affairs*: vol. 18, no. 1, January/February 1999: pp. 107-117.

⁶² D. Yee, *Asian and Pacific Islander Elders in the U.S.: An Annotated Bibliography*, National Asian Pacific Center on Aging, in D. Yee, *Medicare Beneficiary Grassroots Rights and Protections Outreach Project for Vulnerable Populations*, *ibid*.

⁶³ D. Yee and A. Shin, *Information Resources Among Asian and Pacific Islander Elders: An Environmental Scan*, National Asian Pacific Center on Aging, in D. Yee, *Medicare Beneficiary Grassroots Rights and Protections Outreach Project for Vulnerable Populations*, *ibid*.

Yee and Shin report that these findings are consistent with five common service access barriers they cite in the literature: 1) limited English proficiency in the context of a monolingual English service delivery and information system; 2) cultural differences that result in a lack of service access and misunderstandings about how service systems operate (e.g., eligibility or application procedures and service delivery protocols); 3) marginal literacy in a language other than English or in English which makes the government's reliance on informing beneficiaries via print materials not useful; 4) immigration status which raises uncertainty among service providers and API elders about eligibility and entitlement to government health insurance, financial assistance, and service programs; and 5) historical patterns of service delivery and program administrators who are not able to and are sometimes disinterested in accommodating the diversity of populations they are commissioned to reach and serve.⁶⁴

The research literature also suggests that information materials and channels may be barriers to use for certain beneficiary sub-groups. We review these findings in the following sections.

Beneficiaries Use Both Formal and Informal Sources of Information: Different Sub-groups Prefer and Use Different Sources, Formats, and Channels, Reflecting Multiple Factors and Individual and Sub-group Preferences.

It has been widely reported that beneficiaries depend on multiple information sources for knowledge about Medicare. These information sources include materials and content used by beneficiaries as well as the formal and informal information supports that play a significant role helping them overcome potential barriers to their own personal knowledge and decision making capabilities regarding their Medicare choices. Few studies have examined knowledge and use of services, or the effectiveness of various information approaches and their use with beneficiary sub-groups. While some suggest directions and trends in beneficiaries' use of information sources and knowledge, we were not able to identify any studies that tied use of specific information materials and channels to beneficiaries' knowledge and decision making about their Medicare choices. Rather, most studies report that beneficiaries use multiple sources of information, and no one source is said to have a greater or lesser impact on these outcomes. The number and type of source, as well as how information is presented all appear to influence knowledge. Whether and how this knowledge may affect decision making has not been systematically addressed.

The few studies that have addressed special populations' use of Medicare information confirm reports by site monitoring researchers, advocates, and beneficiary educators who report that different beneficiary segments prefer and use different information sources and channels, and that some are likely to be more effective than others in reaching beneficiaries with special information needs. This is particularly evident in beneficiary sub-groups with special cultural and language requirements, but applies equally to beneficiary sub-groups identified according to other criteria, such as disability type, other minority status, and individual or group status on entry to the Medicare program. As we found to be the case with research addressing these issues for the Medicare population as a whole, there has been virtually no systematic evaluation of specific interventions, and limited evidence to help target NMEP information activities to these populations.

⁶⁴ Lavizzo-Mourey & Mackenzie, 1996; Tirado, 1996; cited in Yee and Shin, 1999, *ibid*.

Sangl and Wolf,⁶⁵ in their overview of consumer information and decision making, describe consumers' health decisions as interactive and complex. Information needed comes from a variety of sources and requires different community foci, styles, and strategies to meet the needs of various groups. Consumers rely extensively on informal sources of information such as family and friends to help them make these decisions. To supplement these traditional information sources, formal sources of information have been expanding to assist consumer decision making.

A range of formal information and outreach approaches have been developed to help inform beneficiaries about Medicare benefits and plan choices. Abt Associates' monitoring of sites and REACH program activities has documented formats and methods that include print materials, audio and video tapes, group presentations, health fairs, van tours, and others.⁶⁶ Similar diversity has been reported in site monitoring studies by researchers at Mathematica Policy Research⁶⁷, who conclude from their findings that "the ultimate effectiveness of...Medicare education activities depends not only on *what* is said, but on how it is presented." Research consistently shows that, for a majority of beneficiaries, this means one-on-one counseling or counseling in small groups that addresses their specific information needs and concerns.⁶⁸ As participants in focus groups conducted by the National Academy of Social Insurance (NASI) and the California Health Care Foundation told researchers, they wanted information presented by neutral people who were unattached to plans and would give them a chance to talk.⁶⁹

Beneficiaries' Knowledge Appears to Involve a "Cumulative" Effect of Multiple Sources, in Combination with Individual and Sub-group Preferences. There is No Evidence About the Relative Effectiveness of Any One Specific Approach in Improving Knowledge or Decision Making.

Hibbard et al⁷⁰ report that, on average, respondents in her five managed care study markets used three of the following ten information sources in choosing a health plan: consumer groups other than AARP, Medicare, physicians or other healthcare professionals, AARP, TV, employer or former employer, newspaper or magazine, friends or family, HMO ads, experience in an HMO. Enrollees in HMOs most frequently cited 1) experience in an HMO, 2) HMO ads, and 3) friends or family as information sources. Traditional Medicare enrollees cited 1) HMO ads, 2) newspaper or magazine articles, and 3) friends or family as their most frequently used sources. Knowledge assessments conducted as part of the study showed that 30 percent of respondents knew almost nothing about the Medicare program and their Medicare+Choice

⁶⁵ J. Sangl and L. Wolf, "The Role of Consumer Information in Today's Health Care System," *Health Care Financing Review*, vol. 18, no. 1, Fall 1996: pp. 1-8.

⁶⁶ Abt Associates briefings and unpublished reports of NMEP activity and site monitoring conducted for CMS, 1998-2001.

⁶⁷ B. Stevens and J. Mittler, *Making Medicare+Choice Real: Understanding and Meeting the Information Needs of Beneficiaries at the Local Level*, op. Cit.

⁶⁸ National Health Policy Forum Issue Brief, *Communicating to Beneficiaries about Medicare+Choice*, op.cit.

⁶⁹ National Health Policy Forum Issue Brief, *ibid.*, p 5.

⁷⁰ J. Hibbard et al, "Can Medicare Beneficiaries Make Informed Choices?" *Health Affairs*, vol. 17, no. 6, November/December 1998: pp. 181-193.

plans. The survey identified several factors associated with knowledge. Education correlated with knowledge, followed by income, enrollment type, number of information sources, and gender. Males, traditional Medicare enrollees, those who use more information sources, and those with higher education and incomes had higher knowledge scores. Using more information sources was associated with greater knowledge. Those who used information from consumer groups and newspapers or magazines had significantly higher knowledge scores than those who did not use these sources. However, no one source appeared to produce higher knowledge scores. Hibbard concludes it is not just the number but the type of source used that influences knowledge.

Yee and Shin⁷¹ address similar issues for the Asian Pacific Islander population. To assist efforts to target “hard to reach” API groups about health and non-health-related services and products, Yee and Shin asked respondents to rank the success or effectiveness of various media methods. While some differences were reported for specific API groups (Chinese, Filipino, Japanese, Korean, Vietnamese, Cambodian, Pacific Islander, Other API), findings for all API groups show the following rankings, in order of response: 1) family, 2) friends, 3) newspaper, 4) word-of-mouth, 5) others, 6) newsletters, 7) in person, 8) radio, 9) telephone, 10) religious group and TV (tied). Informal and personalized methods for conveying information were mentioned more often than conventional mass media such as radio, television or newspapers. Newspapers and newsletters were rated almost as highly as informal personalized methods (in person, family, friends, and word-of-mouth, others), but the authors emphasize that much depends on the availability of these media in local communities. Few examples were provided of successful marketing campaigns targeting a “hard to reach” API group.⁷²

When respondents were asked to provide suggestions for culturally competent methods a government agency might take to effectively distribute information about Medicare, almost twice as many respondents encouraged the agency to work with API community religious and civic organizations, and to collaborate with API organizations compared to respondents who suggest materials be translated and disseminated or that the government agency work with the API language media. Few respondents suggested that the government agency hire bilingual staff to develop materials in-house or to conduct direct mailings to API elders.⁷³

Yee and Shin also asked respondents to assess how or whether different strategies would need to be considered to reach and inform/educate Medicaid or dual eligible API elders. Only 11 responses were provided; three mentioned outreach strategies that might involve schools. Yee and Shin suggest the rationale for this appears to be linked with the notion that many elders live with adult children and provide care for school-age grandchildren.

⁷¹ D. Yee and A. Shin, *Information Resources Among Asian and Pacific Islander Elders: An Environmental Scan*, National Asian Pacific Center on Aging, in D. Yee, *Medicare Beneficiary Grassroots Rights and Protections Outreach Project for Vulnerable Populations*, op. Cit.

⁷² Long distance phone service was identified as the most successful product marketed to API ethnic groups. One organization was contacted to translate written material, four were contacted about providing a service or conducting a specific program, and 15 had other contact related to discounts for use of a product, product/service marketing or endorsements.

⁷³ Yee and Shin point out that these suggestions rely on a high density of API populations, consistent demand to conduct outreach, information and education campaigns in API languages, and an identified and maintained mailing list.

Study findings indicate that the most successful mode of information dissemination is through family and friends of API elders, then in-person and by word-of-mouth, then by newspaper and newsletter. Yee and Shin provide three perspectives on these findings. The first suggests a trade-off between quantity (mass media) and quality (individual-directed and personalized) in developing information and education campaigns. Messages are best understood when they are conveyed in the context of life experiences of API elders, with information dissemination methods filtered or interpreted and culturally translated by trusted and competent individuals in the elder's social context. The second suggests the importance of conveying messages through reliable messengers who are known and trusted rather than trying to convey anonymous mass media messaging. A third perspective suggests that work with the API language media has real possibilities for success, and that relationships with newspaper and newsletter publishers are the first step in building reliable vehicles for carrying messages.⁷⁴

Research also shows that beneficiaries use and respond to different types of information channels in meeting their information needs. There is little agreement about which channels or approach to use, or to what end, in information campaigns. A consistent theme in most studies, including research cited above by Yee and Shin, is that information should be targeted to the context of peoples' situations and life experiences, across demographic and other categories. Lubalin and Harris-Kojetin's⁷⁵ review of the literature on this topic also concludes that this is necessary to create an understandable context within which to interpret comparative information for beneficiary choice.

Information Intermediaries and Local Supply Networks—Research is Needed on the Roles and Information Needs of Intermediaries, and How to Effectively Support Intermediaries in Providing Information and Outreach to Diverse Beneficiary Sub-groups.

The importance of intermediaries such as advocates, community organizations, family members and healthcare professionals has been widely recognized in the design and implementation of the NMEP, its national and regional partnerships, and research studies that address Medicare information activities to support beneficiary choice. Intermediaries help to bridge the knowledge gap for beneficiaries who are unable or who do not want to absorb and understand information about the Medicare program and plan choices directly. However, little is known about their information needs and roles at the local level, and how to effectively support intermediaries in information outreach and education to general Medicare beneficiaries or special population sub-groups. Further, the few studies that address information intermediaries, a secondary audience for NMEP information, indicate that many lack adequate Medicare knowledge, or the resources to effectively assist beneficiaries in their decision making about healthcare.

Hibbard and Jewett, like researchers at Abt Associates and Mathematica Policy Research, observe that in most communities, the existing infrastructure for outreach through

⁷⁴ Yee and Shin state, "When an organization relies only on need-driven and crisis-oriented opportunities to "use" publications to disseminate messages, the opportunities to develop specific, complex and multi-message information dissemination opportunities (i.e., more education oriented approaches) are lost.

⁷⁵ J. Lubalin and Harris-Kojetin, 1999, p. 90.

intermediaries is underdeveloped and under-funded, and relies heavily on volunteers.⁷⁶ Much of the discussion on this topic is directed to State Health Insurance Programs (SHIPs) and their roles in the NMEP campaign as REACH information partners. Together with CMS contractors such as carriers, Peer Review Organizations, fiscal intermediaries, and other organizations, SHIP grantees participate in the NMEP as front line REACH program partners at the state and local levels. Since 1992, SHIPs in 49 states, two territories and the District of Columbia have received State Information, Counseling, and Assistance (ICA) funding from CMS to help support Medicare education and outreach. Some state programs pre-date CMS funding and have developed strong programming and funding support from state and other sources. However, most programs operate with a limited budget. All rely on volunteer networks to provide beneficiary counseling and outreach. In a review of these programs prepared prior to the NMEP, McCormack et al⁷⁷ observed that as awareness increases and the field of consumer information grows, demand for SHIP services may outrun program capacity, and programs will need to develop new ways to address increased demand.

Researchers, policy and program experts and advocates generally agree that intermediaries play a crucial role in reaching beneficiaries with special information needs, as reports cited previously by Yee and others demonstrate. Few studies have been conducted that examine intermediary linkages and roles in providing information support to these beneficiary sub-groups. Mathematica's site monitoring described word-of-mouth and informal communication at community institutions as key paths to education in minority communities, where trust is an important issue, especially those that have experienced a history of formal and informal discrimination and segregation.⁷⁸

Stevens and Mittler report that advocacy organizations that represent vulnerable beneficiaries such as ethnic minorities, the disabled, or the low literate, were rarely actively involved in Medicare education in Mathematica's six monitoring sites. While local intermediaries reportedly recognized the need to alter their information and format to fit the information preferences of different beneficiary groups, few were able to do so. Mathematica's site monitoring indicates that intermediaries have made some efforts to address the needs of beneficiaries with sight or hearing impairments, but broad scale adjustments had not been accomplished.

Partners'/Intermediary's Knowledge of Medicare. Effective use of intermediaries requires that intermediaries have adequate knowledge of Medicare. However, knowledge among beneficiaries as well as their informal support networks is often deficient in content and scope. Research addressing this topic is sparse for the general Medicare population as well as for beneficiary sub-groups. We identified one study that addressed this issue among adult children of beneficiaries, who with peers, other family members and friends play an especially important role in seniors' decision making about healthcare. This study, a survey conducted by the Henry

⁷⁶ Hibbard and Jewitt, op. Cit., p. 191; Abt Associates, briefings and unpublished reports of NMEP activity and site monitoring conducted for CMS, 1998-2001; B. Stevens and J. Mittler, *Making Medicare+Choice Real: Understanding and Meeting the Information Needs of Beneficiaries at the Local Level*, op. Cit.

⁷⁷ L. McCormack et al, "Medicare Beneficiary Counseling Programs: What Are They and Do They Work?" *Health Care Financing Review*, vol. 18, no. 1, Fall 1996: pp. 127-140.

⁷⁸ B. Stevens and J. Mittler, op. Cit.

J. Kaiser Family Foundation/Family Circle Magazine⁷⁹, showed that 43 percent of surveyed adults said they knew “next to nothing or nothing at all” about health insurance to help their parents. This survey also showed that adults with aging parents displayed limited knowledge of government health programs. Most correctly identified the Medicare program, but only 38 percent knew that Medicare generally does not pay for prescription drugs, and only 34 percent knew that Medicare does not pay for long term care. Meanwhile, the survey reported that, of the adults surveyed with a parent >65 years of age, 43 percent said their parent would be most likely to turn to themselves, other family members, or friends for health insurance information.⁸⁰

Professional intermediaries may also lack knowledge needed to assist beneficiaries’ decision making. A Families USA Foundation⁸¹ study showed that both professionals and beneficiaries lack knowledge of programs available to expand options to low income beneficiaries, such as Medicaid QMB/SLMB and QI-1 programs.⁸² Significant numbers of beneficiaries eligible for these programs are not receiving benefits. Study findings show that:

- Nationally, between 3.3 and 3.9 million of the 8 million low-income Medicare beneficiaries (41.5-47.9 percent) eligible for QMB and SLMB benefits are not receiving them.
- An estimated 1.6 million beneficiaries qualify for QI-1 buy-in. As of June 1998 fewer than 1 percent of potentially eligible beneficiaries received this benefit.

This study attributes low participation in these buy-in programs to lack of knowledge about the programs on the part of both beneficiaries and social workers, bureaucratic hurdles, and complex enrollment systems that are difficult for many to navigate. State Medicaid programs have little incentive to do outreach because states must pay 45 percent of the buy-in cost. Medicare beneficiaries must visit a Social Security office to enroll in Medicare; they are not allowed to apply for buy-in benefits at that office, and must make a separate trip to a welfare office. This study reports that many seniors report difficulties finding individuals in welfare or Social Security offices who know about these programs. Even in states where application can

⁷⁹ Henry J. Kaiser Family Foundation/Family Circle Magazine survey, cited in Bureau of National Affairs, Inc., vol. 8, no. 39, October 2, 2000.

⁸⁰ Meyer points out that, while consumer reliance on family and friends rather than hard data on performance has been well documented, this information may not always be reliable. The challenge, he states, is to meet consumers where they are but at the same time try to move them to a higher plateau. Another challenge is to be patient as efforts to improve the way consumers make decisions evolves gradually. (J. Meyer, “Commentary,” *Medical Care Research and Review*, Vol. 56, Supplement 1: 1999: pp. 103-107.

⁸¹ Ibid.

⁸² State Medicaid programs offer three major categories of buy-in programs to assist low income Medicare beneficiaries: 1) Qualified Medicare Beneficiaries (QMB): Individuals with incomes at or below the poverty level are eligible for financial assistance to cover Medicare premiums, deductibles, and co-payments; 2) Specified Low-Income Medicare Beneficiaries (SLMB): Individuals with incomes between 100 and 120 percent of poverty are eligible for assistance in their Medicare Part B premiums only, 3) Qualified Individuals (QI-1): Medicare beneficiaries with incomes between 120 and 135 percent of poverty are eligible through a block grant program to apply for payment of their Medicare Part B premiums. This program serves potentially eligible persons on a first-come, first-served basis. Due to limited funds in the block grant, only a portion of those who are eligible for the benefit will actually receive it.

be made by mail, forms are difficult to understand for many beneficiaries, and extensive documentation is required.

Yee *et al.*⁸³ suggest that if the percentage of those eligible for QMB and related programs is low for beneficiaries, overall, it is likely to be substantially lower among limited English-speaking immigrants, such as Asian Pacific Islanders. Further, welfare reform legislation in 1996 disqualified many immigrants from some state and Federal benefits. This makes them more distrustful of government, and hard to reach.

This research also suggests that different outreach strategies may be required for those receiving Social Security compared to those not receiving Social Security, for which many elder immigrants do not qualify.

“Those not receiving Social Security who have low incomes are more likely to need information and assistance with applications to “buy-in” to Medicare because they are over 65 and eligible for Medicaid. Because most service providers in the U.S. assume that all older persons over age 65 have Medicare, they often are unaware of provisions that help make healthcare more affordable among those not entitled to Medicare.”⁸⁴

Research and work with advocates in the Asian Pacific Islander (API) community indicates that misinformation about Medicare and Medicaid increases exponentially as these programs grow in complexity. Issues raised in research by Yee et al include: how citizenship status affects eligibility for Medicaid and Medicare buy-in provisions, what to expect in terms of insurance program coverage and out-of-pocket costs when seeking medical care, how to know which providers accept Medicare and Medicaid. According to this study, these issues are secondary to basic information about basic Medicare, new Medicare options, and Medicaid. Yee et al conclude, “Materials and outreach campaigns for poor and low income API elders that address these issues in ways that accommodate language, culture, and learning formats of the various API elders appear to be a first step in assuring access to healthcare and in addressing healthcare affordability for these diverse ethnic groups.”⁸⁵

Intermediaries as a Link to Special Populations: Community Organizations Serving Special Populations Often Lack Connection to Mainstream Information Providers—a Crucial Link to Successful Medicare Information and Education.

The research literature identifies problems as well as successful ways that intermediaries can be used effectively with certain beneficiary groups, although few studies have examined these issues systematically. For example, research consistently shows that elders who successfully get into a system and successfully navigate language and other barriers are more likely to get additional information and be referred to needed services. In API and other cultural and linguistic communities, local community-based organizations are most able to consistently reach elders least able to access monolingual English “mainstream” service and administrative

⁸³ D. Yee, D. Rose, and K. Bostock, “Asian and Pacific Islander Elders in the U.S.: A Demographic Report,” *Medicare Beneficiary Grassroots Rights and Protections Outreach Project for Vulnerable Populations*, National Asian Pacific Islander Center on Aging, with PRO-West, National Indian Council on Aging, and RAND, for CMS, 1999.

⁸⁴ Ibid., p. 57.

⁸⁵ *National Asian Pacific Islander Center on Aging, 1998, cited in D. Yee, ibid.*

agencies. However, many channels for special populations are isolated from mainstream information networks. In API communities, for example, Yee's community assessments found that most interaction between formal service systems and specific ethnic community groups was reported as low where community-based API language service providers are established. Otherwise it was nonexistent.⁸⁶

Mathematica's⁸⁷ site monitoring work shows that beneficiaries with disabilities under 65 years of age are somewhat "invisible" members of the Medicare population, and the organizations that serve disabled communities in all six sites operate largely separately from the senior network. Further, people with disabilities do not feel Medicare "works" for them, in part because education and marketing are directed primarily to seniors and because the names of Medicare managed care products commonly contain the words "senior" and "65" in them. Advocates for the disabled and Medicare+Choice managed care organizations noted that most mainstream Medicare educators and most Medicare+Choice managed care organizations make only minimal efforts to reach out to people with disabilities.

Evidence about how best to support intermediaries in their efforts to provide information outreach and education to beneficiaries with special information needs is generally limited to anecdote from field-based practitioners, and little is known about the effectiveness of specific methods and approaches. As an initial exploration of these issues, Barents Group⁸⁸ examined the processes used by effective organizational intermediaries in the NMEP. Study findings showed that effective organizations use formal methods such as surveys and focus groups as well as periodic discussions with customer service representatives, and collect and disseminate studies, articles, and other information on the target population. Effective organizations also include customer feedback or use of materials and services as part of their ongoing quality improvement process.

At a more applied level, site monitoring studies may be useful in helping to identify specific approaches worthy of more formal evaluation of program process and effectiveness. Field-based studies also suggest best practices that may be adapted to other sites and sub-groups to assist local efforts in serving the information needs of special populations.

⁸⁶ D. Yee, *ibid.*, p. 8.

⁸⁷ B. Stevens and J. Mittler, *op. Cit.*

⁸⁸ Barents Group, *op. Cit.*

Study	Data Collection Methods	Special Population Information Deficits Identified
Appendix Table A.2 Research and Reports on NMEP/REACH Special Information Populations		
Institute of Medicine, 1999	Presentations of research by policy officials, advocates, researchers	<p>Committee considered the following sub-groups that require special sensitivity for NMEP information and outreach:</p> <p>1..Chronically ill individuals in managed care: Presentations were mixed on how managed care organizations address individuals with chronic illness, noting beneficiaries tend to be happier with their primary care provider if they feel comfortable with that person and that they also rate their satisfaction with a health plan higher if they do not use it much.</p> <p>2.Immigrants for whom English is not their primary language and those with low literacy: In addition to language barriers, immigrants face the same barriers to understanding and choosing a health plan as native born beneficiaries, as well as economic and legal barriers to care, and bring different cultural approaches to health and health care, and tend to have lower levels of literacy, particularly written English.</p> <p>3.Cognitively impaired individuals: For individuals with dementia or mental retardation it is important to make sure family members are provided with good information.</p>
Kleimann, 1998	Focus groups, secondary sources	People who cannot sort through mounds of definitions and facts and figures, and who will be overwhelmed by too much information—probably 98 percent of the beneficiaries. For people with low literacy skills, cognitive impairments, problems with vision, people who do not speak English or do not feel comfortable dealing with complicated issues in English, understanding Medicare options will be especially intimidating.
Barents Group, 1999	Focus groups, MCBS analyses	<p>Barents provides profiles of the following sub-groups:</p> <ol style="list-style-type: none"> 1.African American beneficiaries 2.Hispanic American beneficiaries 3.Beneficiaries who are dually eligible for Medicare and Medicaid 4.Beneficiaries who live in rural areas 5.Beneficiaries with vision impairments 6.Beneficiaries with hearing impairments 7.Beneficiaries with a limited education or low literacy skills <p>Key findings are shown in Table A.3, following.</p>

Neuman and Langwell, 1999	Policy review of secondary sources	<p>1.Beneficiaries with limited education, serious limitations in cognitive functioning, and those in poor health: This group may find information confusing and difficult to use-- as high users of services they may face serious consequences if care is disrupted, if they lose access to specialists or cannot find affordable care.</p> <p>2.Low income beneficiaries: This group may not have financial resources to choose based on quality, access to doctors or benefits—as consumers whose choices are likely to be dictated by price, they may face disruptions in care, poorer quality of care, and lower levels of satisfaction, and are likely to be disproportionately affected by plan premium increases.</p> <p>3.Economically disadvantaged beneficiaries who may be eligible for both Medicare and Medicaid, and managed care under both programs: This group is dependent on information about eligibility and coordination of program benefits—as consumers dependent on information about eligibility and coordination of program benefits they may face difficulties navigating, enrolling in, and receiving benefits.</p>
Vulnerable Medicare Populations—Health Status, Services, and Insurance Coverage		
MedPAC, 2000	1998 MCBS analyses	Beneficiaries found to be more vulnerable to access problems under Medicare include African Americans, Hispanics, functionally disabled, in poor health, poor, or lacking supplemental insurance. Medicare managed care enrollees' access to services varied based on health, functional, or disability status rather than race, ethnicity, or income. Evidence of access problems for rural beneficiaries was mixed. Traditional Medicare beneficiaries, overall, were satisfied with their healthcare, but beneficiaries in fair or poor health, those needing assistance with functional impairment, disabled, or lacking supplemental insurance were less satisfied. Decreased satisfaction found among Hispanics, persons with income < \$10,000, and urban residents. Information needs not specified for general Medicare population or beneficiary sub-groups.
Henry J. Kaiser Family Foundation, <i>Faces of Medicare</i> (current)	1997 MCBS analyses	<p>-More than 40 percent of African American and Latino seniors perceive their health status as fair or poor (vs. 25 percent of whites), more than 1 in 6 has functional limitations (compared with 1 in 10 whites), minority beneficiaries are more likely than whites to report having cognitive impairments, with no difference between men and women.</p> <p>-About 1/3 of minority beneficiaries live below the poverty level (more than 3 times the share of whites), and nearly 2/3 of African American and Latino beneficiaries have incomes <2 times the poverty level (vs. 41 percent of whites).</p> <p>-Minority beneficiaries are more likely than whites to rely solely on traditional Medicare for coverage, about 1/4 of African American and Latino beneficiaries have no supplemental coverage (vs. 10 percent of whites), 1/3 of African American and 1/4 of Latino beneficiaries have Medigap or retiree benefits (vs. 2/3 of whites). African Americans and Latinos are more likely than whites to rely on Medicaid to supplement Medicare. Information needs not specified for general Medicare population or beneficiary sub-groups.</p>
Kaiser/Commonwealth Fund, 1998	1997 nationally representative survey of 3,309 beneficiaries	-57 percent of beneficiaries were 'very satisfied' with Medicare; fewer than 5 percent said they did not get needed care, 15 percent reported difficulties getting needed care. Access and cost problems were more common among those with low incomes and health problems. Beneficiaries lacking supplemental coverage were more likely to experience problems with access and cost. Information needs not specified for general Medicare population or beneficiary sub-groups.

Knowledge of Medicare and Health Plan Choices		
CMS/OIG, Senate hearings, 1998	Survey of general Medicare population	<ul style="list-style-type: none"> -1/3 of beneficiaries know little or nothing about traditional Medicare benefits or out-of-pocket payments ->40 percent know little or nothing about private supplemental insurance -about 1/3 of beneficiaries did not understand or know about appeals under Medicare -6 of every 10 beneficiaries know little or nothing about managed care Findings describe general Medicare population; beneficiary sub-groups not addressed.
Hibbard and Jewett, 1998; Hibbard <i>et al.</i> , 1998	Survey of 1,673 beneficiaries including enrollees in traditional Medicare and HMOs, residing in 5 Medicare markets with high HMO penetration	<ul style="list-style-type: none"> -30 percent of all beneficiaries knew almost nothing about HMOs -only 11 percent have adequate knowledge to make an informed choice -HMO enrollees have significantly lower knowledge levels of the differences between HMOs and traditional Medicare -income & education are the most significant predictors of knowledge -HMO enrollees had lower incomes and lower levels of education than enrollees in traditional Medicare -Beneficiaries use multiple sources of information, no one source identified as effective impacting knowledge -Those with highest knowledge were men, traditional Medicare enrollees, those who used more information sources, those with higher education and higher income; those with lower knowledge were women, enrolled in an HMO, used fewer information sources, had less education and lower incomes.
Neuman and Langwell, 1999	Policy analysis, review of secondary sources	<ul style="list-style-type: none"> -37 percent of Americans >65 years of age do not know that traditional Medicare does not cover outpatient drugs, 56 percent do not know that Medicare does not cover long term nursing home care, about 1/4 are aware of Medicare+Choice but only 9 percent understand that it provides a greater choice of health plans rather than a greater choice of doctors. (National Survey on Medicare, Kaiser Family Foundation/Harvard School of Public Health) -Minority groups are less likely to understand basic elements of Medicare (Barents Group, 1999)
RTI/HER/Benova, 1994	Literature review of consumer knowledge about healthcare coverage	Most consumers have a basic understanding of their health plan options but much less understanding of the more detailed and complex issues involved. Few studies looked at or documented beneficiary sub-group differences; those that did reported only that knowledge tended to be higher among persons with higher education, those more experienced with their healthcare system, and those who receive more information.
Mathematica Policy Research, 2000	Site monitoring case studies in 6 urban managed care markets	<ul style="list-style-type: none"> -Beneficiaries try to understand only as much as is directly relevant to their circumstances and rarely seek information unless there is some sort of change or crisis internal or external to their lives. Most make decisions on the basis of basic information about the cost of coverage, whether their physician is in a plan, and whether there is prescription drug coverage.

Abt Associates, 1998-2001	Site monitoring case studies in 6 study sites; monitoring studies of REACH program activities	<p>-Beneficiaries fear change, worry about their ability to understand and cope with it, and tend to remain with their existing arrangements as long as possible, until continuing with the <i>status quo</i> is no longer possible.</p> <p>-Beneficiaries seek information only when specific needs arise. Few make the effort to learn about new options.</p> <p>-When beneficiaries do seek information to resolve a problem, they typically want to be told what the best course of action is for their situation, not be given complicated information about how to think about their options.</p> <p>-Beneficiaries tend to have a limited 'information horizon' and may make choices based on informal channels or plan marketing materials; they are often only vaguely aware of independent information sources and are not motivated to use these sources.</p>
Yee et al, 1999	<i>Medicare Beneficiary Grassroots Rights and Protections Outreach Project</i> : annotated bibliography on minority seniors' needs and use of information, community surveys, focus groups, needs assessments, environmental scans of Asian Pacific Islander elders and organizations	<p>Bibliographic annotation profiles minority elders' information and service needs (Yee, 1999).</p> <p>A survey of 3,500 Asian Pacific Islander (API) elders and community leaders in WA re: elders' experiences getting information and gaining access to needed health and social services showed:</p> <p>-The top 5 areas elders believe to be most problematic are 1) language access, 2) enough money to live on, 3) affordable housing, 4) transportation availability, and 5) employment. (Yee and Shin, 1999).</p> <p>In a second study of more than 4,000 API elders conducted over 2 years in 5 metropolitan areas nationwide:</p> <p>-The top 5 areas ranked by elders as most problematic include: 1) lack of information about services, 2) language barriers, 3) access to health information, 4) health services, and 5) transportation (Yee and Shin, 1999).</p> <p>Findings from these studies are consistent with 5 common access barriers cited from the literature by Yee and Shin: 1) limited English proficiency in the context of a monolingual service delivery and information system, 2) cultural differences that result in a lack of service access and misunderstandings about how service systems operate, 3) marginal literacy in a language other than English or in English which makes reliance on print materials not useful, 4) immigration status which raises uncertainty about eligibility and entitlement to government health insurance and other benefits, and 5) historical patterns of service delivery and program administrators who are not able to and are sometimes disinterested in accommodating diversity of the populations they are commissioned to reach and serve.</p>
Moon, 1999	1993 MCBS analysis	<p>-Nearly 1/5 of beneficiaries was in poor physical health in 1993, and nearly 1/4 of all beneficiaries have problems with cognitive functioning, including mental retardation, mental disorder, Alzheimer's disease, or difficulties handling money or talking on the phone.</p> <p>-31.6 percent of all beneficiaries have one or both types of impairments that are likely to compromise their ability to understand key plan differences or make good choices.</p>

Hibbard <i>et al.</i> , 2001	Two separate convenience samples were selected: Medicare beneficiaries age 65 and older (n=253) and a non-Medicare sample ages 18 to 64 (n=239).	More than half of the Medicare population has difficulty using comparative health plan information. Medicare beneficiaries made almost three times as many errors as younger respondents, and there was greater variability, with most in the area of comprehension. Comprehension performance declined after age 80, suggesting both a literacy and an aging effect. Those with poorer comprehension skills were more likely to indicate a desire to delegate decision making about coverage.
Gold <i>et al.</i> , 2001	Survey of 6,620 Medicare beneficiaries selected from CMS's Part A and Part B files over a 15 week period beginning March 2000. Analyses focus on: under-65 disabled, age 85 and older, low and moderate income beneficiaries, those with limited education, African Americans, other races (Asians, Hispanics) those in fair or poor health, disabled beneficiaries, those unable to answer who need a proxy.	Medicare beneficiaries have limited understanding of the basics of Medicare. Knowledge is also low among family members and other informal advisors. Informal sources of information (spouses, family, friends, medical professionals) dominate beneficiaries' decision making. Formal infrastructure locally supporting choice reaches a minority of beneficiaries. Vulnerable sub-groups are less satisfied with their current coverage and more worried about expenses. Poor health and socio-economic vulnerability increase the likelihood that a beneficiary will consider choice.
Consumer Search Behavior		
Barents Group, 1999	Focus groups	<p>-Examines beneficiaries' information-seeking styles as proactive, reactive, and passive with suggested methods for NMEP information and education.</p> <p>-Beneficiaries have 3 types of information needs: 1) basic information needs, such as whether and how to enroll in various Medicare options; 2) navigational information needs, such as how to make the best choice among plans or providers; and 3) situation-specific information needs, such as locating a participating physician in an area, whether coverage for specific services or equipment is provided, or out-of-pocket costs associated with specific healthcare needs.</p> <p>-Beneficiaries' information needs and preferences evolve over time, moving through several stages and decision points, e.g., <i>pre-enrollment, enrollment, users, and reconsideration of enrollment.</i></p>

Pro-Change, 2000	Cross-sectional and longitudinal analyses of MCBS, 1996, 1997, 1998 for construction of algorithms	<p>Applications of stages of change—pre-contemplation, contemplation, preparation, action, and maintenance—show:</p> <ul style="list-style-type: none"> -Beneficiaries are furthest along in readiness to learn about Medicare (44 percent in Action stage). -Beneficiaries are less ready to learn about availability and benefits of HMOs (27 percent in Action stage) and to review health plan options (12 percent in Action or Maintenance). -Stage of change was related to knowledge about Medicare, information seeking, and most variables (e.g., income and education) expected to vary with stage. -Stage of change was a better predictor of knowledge about Medicare than all demographic, health status, and health plan variables examined, even education. -Stages of change for learning about Medicare HMOs were the best predictors of knowledge about Medicare HMOs.
Center for Health Systems Research and Analysis/RTI, 2000	MCBS analyses for 1995, 1996, 1997, 1998	Using MCBS data, 6 measures were created re: beneficiaries' knowledge of Medicare. An 8-item quiz provided the best indicator of beneficiary knowledge, providing more power to discriminate among and within beneficiaries. This study is part of a larger effort to develop a knowledge index for evaluation of the <i>Medicare and You</i> Handbook and other NMEP materials.
Beneficiaries' Knowledge and Use of Information		
Hibbard and Jewett, 1998; Hibbard <i>et al.</i> , 1998	Survey of 1,673 beneficiaries including enrollees in traditional Medicare and HMOs, residing in 5 Medicare markets with high HMO penetration	<ul style="list-style-type: none"> -On average, respondents used 3 of the following 10 information sources in choosing a health plan: consumer groups other than AARP, Medicare, physicians or other healthcare professionals, AARP, TV, employer or former employer, newspaper or magazine, friends or family, HMO ads, experience in an HMO. -HMO enrollees most frequently cited: 1) experience in an HMO, 2) HMO ads, and 3) friends or family. -Traditional Medicare enrollees most frequently cited: 1) HMO ads, 2) newspaper or magazine articles, and 3) friends or family. <p>Several factors were associated with knowledge: education, income, enrollment type, number of information sources, and gender. Males, traditional Medicare enrollees, those who use more information sources, and those with higher education and incomes had higher knowledge scores. Using more information sources was associated with greater knowledge. Those who used information from consumer groups, newspapers and magazines had higher knowledge scores than individuals who did not use these sources. No one information source appeared to produce higher knowledge scores.</p>
Yee and Shin, 1999	Environmental scan of API elders	<p>Respondents ranked the success or effectiveness of the following media methods for information (in order): 1) family, 2) friends, 3) newspaper, 4) word-of-mouth, 5) others, 6) newsletters, 7) in person, 8) radio, 9) telephone, 10) religious group and TV (tied). Informal and personalized methods were mentioned more frequently than conventional mass media.</p> <ul style="list-style-type: none"> -When asked about culturally competent methods government might use to distribute Medicare information, almost twice as many respondents encouraged the agency to work with API organizations compared to respondents who suggest materials be translated and disseminated or that the government agency work with API language media.

Information Intermediaries' Knowledge of Medicare		
Henry J. Kaiser Family Foundation/Family Circle Magazine, 2000	Survey of adults with aging parents	<p>-43 percent of surveyed adults said they knew 'next to nothing or nothing at all' about health insurance to help their parents.</p> <p>-Most correctly identified the Medicare program, but only 38 percent did not know that Medicare does not pay for prescription drugs, and 34 percent knew that Medicare does not pay for long term care.</p> <p>-Of the adults surveyed with a parent >65 years of age, 43 percent said their parent would be most likely to turn to themselves, other family members or friends for health insurance information.</p>
Families USA, 199_	Analysis of CMS data, survey interviews	<p>-Nationally, between 3.3 and 3.9 million of the 8 million low-income Medicare beneficiaries (41.5-47.9 percent) eligible for QMB and SLMB benefits are not receiving them.</p> <p>-An estimated 1.6 million beneficiaries qualify for QI-1 buy-in. As of June 1998 fewer than 1 percent of potentially eligible beneficiaries received this benefit.</p> <p>Low participation in buy-in programs is attributed to lack of knowledge about the programs by beneficiaries and social workers, bureaucratic hurdles, and enrollment systems that are difficult to navigate.</p>
Yee <i>et al.</i> , 1999	Community assessments	<p>-Misinformation about Medicare and Medicaid is considerable in API communities. Beneficiary issues include: how citizenship status affects eligibility for buy-in, what to expect in terms of insurance program coverage and out-of-pocket costs, how to know which providers accept Medicare and Medicaid.</p> <p>-Most interaction between formal service systems and specific ethnic community groups was reported low where community-based API language service providers are established. Otherwise it was non-existent.</p>
Mathematica Policy Research, 2000	Site monitoring case studies in 6 urban managed care markets	<p>-Beneficiaries with disabilities under age 65 are somewhat 'invisible,' and organizations that serve disabled communities in all 6 sites operate largely separately from the senior network. Advocates noted that most mainstream Medicare educators and M+C plans make only minimal efforts to reach out to people with disabilities.</p>

